The eMBRACE Study
Motivators & Barriers of Referral to Australian Cancer Genetics

Information Brochure

“Medicine is not merely a science but art. The character of the physician may act more powerfully upon the patient than the drugs employed – Paracelsus”
To improve clinical care and management

The eMbrACE study investigates the barriers of referral of patients diagnosed with endometrial, ovarian and/or colorectal cancer for genetic services via a web-based survey. Genetic services refer to the delivery of genetic risk assessment, counselling and testing for patients and families with, or at high risk of hereditary syndromes.

The survey aims to explore current knowledge and attitudes of health professionals like you towards the use of genetic services. This survey is anonymous. It will take 10-15 minutes to complete, and consists of three sections with questions related to you and your practice.

This study is not a government-sponsored study. However, the results may provide the Australian Government, non-government and health industry partners with an evidence base to improve clinical care and management for patients with or at high risk of Lynch syndrome.

This study has been reviewed and approved by Medical Research Ethics Committee of The University of Queensland (No. 2011000430) and Royal Brisbane & Women’s Hospital (HREC/10/QRBW/490). Should you wish to discuss the study in relation to your rights as participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, HREC, Royal Brisbane & Women’s Hospital, Brisbane 4029, Queensland (Phone 07 3646 5490 or Email ethics@health.qld.gov.au).

Lynch syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC) syndrome, is an autosomal dominant inherited syndrome caused by mutations in one allele of the mismatch repair (MMR) genes MLH1, PMS2, MSH2 and MSH6. Individuals who inherited the gene mutation have a 50% risk of passing the mutation on to their children.

While colorectal cancer is the most common cancer affecting both men and women who inherited the MMR gene mutation, women face additional risks of developing endometrial and/or ovarian cancers. Women with Lynch syndrome have a 40-70% lifetime risk of endometrial cancer compared with 3% in the general population. They also have a 12-15% lifetime increased risk of developing ovarian cancer, which often appears symptomless and can be difficult to diagnose. Increased risks of other cancers also include those of the stomach, pancreas, kidney/ureter/hepatobiliary tract, gastric, prostate, gall bladder and brain.

Identification and referral of mutation carriers are therefore important to facilitate optimal clinical management of the patient and their at-risk family members. Once a mutation carrier is identified, options such as colonoscopy, gastroscopy or prophylactic surgery could be offered to reduce risk of cancer. Regular surveillance could result in decreased disease-specific morbidity and mortality for patients and their family members with or at high risk of Lynch syndrome.
The study is being conducted by the following researchers:

Ms Yen Tan, Doctoral Candidate, The University of Queensland School of Medicine, Brisbane (Principal Investigator)

Prof Andreas Obermair, Director, Queensland Centre for Gynaecological Cancer Research, The University of Queensland School of Medicine, Brisbane

A/Prof Amanda Spurdle, Lab Head, Molecular Cancer Epidemiology, Queensland Institute of Medical Research, Brisbane

A/Prof Julie McGaughran, Director, Genetic Health Queensland, Queensland Health, Brisbane

Dr Lisa Fitzgerald, Public Health Sociologist, The University of Queensland School of Population Health, Brisbane

Do I have to participate?

Participation in this study is voluntary. You may withdraw at any time of the study without having to give any reason. On deciding to withdraw, all relevant data collected will be returned to you and any copies held will be destroyed immediately. The choice that you make will have no bearing on your role and involvement with The University of Queensland, Queensland Centre for Gynaecological Cancer Research, Genetic Health Queensland, Royal Brisbane & Women’s Hospital or Queensland Institute of Medical Research.

If you agree to participate in this study, we will ask that you read this Information Brochure further.
How can you participate?

You can participate by completing the survey online at: The eMBRACE Survey. Follow the instructions to complete the survey, and click the Submit button to submit your completed survey. The survey is anonymous. It will take 10-15 minutes to complete, and consists of three sections with questions related to you and your practice. If you would like to receive a copy of the research summary report, we will ask for your email address at the end of the survey.

What are the benefits associated with my participation?

Whilst there are no direct benefits for participating in this study, your input will provide important information to improve clinical care and management for patients with or at high risk of Lynch syndrome.

Are there any risks involved?

There are no risks associated with your participation in this study. You will be asked to share with us some personal opinions or experiences. You may skip questions and move on to the next if you do not wish to answer the questions.

What will happen to the information I provide?

All information provided will be treated as strictly confidential during and after the project. We will not be sharing information about you or what you tell us to anyone outside of the Research Team. Upon completion of the study, a copy of the research summary report will be made available to you upon request. The results will be used to write a thesis, and may be published in peer-reviewed journals or presented at relevant national or international conferences.

Will my participation in this study be kept confidential?

Yes. We are committed to making sure that information about you is kept safe and in strict confidence. Any identifiable information collected about you in connection with this study will remain confidential and will be disclosed with your permission, or except as required by law. The study will be conducted online on a secure website administered by Ms Yen Tan. All participant data will be kept strictly confidential and participants' email address will be stored separately from their questionnaire responses. Nothing that can identify you will ever appear on any public or published reports.

Security of the data

Only the Principal Investigator will have access to participants' data and these will be stored securely in a password-protected database at the University’s computer network. Upon completion of the study, data collected will be stored securely for a period of 5 years and will be deleted thereafter.

Informed consent

Due to the nature of the data collection, we are not obtaining written informed consent from you. Instead, we assume that you have given consent to participate in the study when you click the Submit button.

After reading the information, we hope that you will be able to participate in this exciting study. It is only through clinicians like you that we can improve future clinical care for women and their family.
For questions about participation or about the study, please contact:

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