

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: “Pelvic and widespread pain in people with Mayer-Rokitansky-Kuster-Hauser (MRKH) syndrome”

We are inviting you to participate in a study addressing pelvic pain and widespread pain in people with MRKH. If you have been diagnosed with MRKH, we would like to invite you to participate in a voluntary, anonymous, online survey regarding your experience of pain. We will also be asking a range of questions that relate to your experience with widespread and pelvic pain and the implications of this pain on aspects such as lifestyle and general health.

Why are we doing this study?

Chronic pain conditions affect many people in the community and are reported to be present in women more often than men. There is minimal information regarding the experience of women with MRKH and whether their pain problems are similar, which is relevant as many pain problems vary with the menstrual cycle. Information regarding people with MRKH may be useful in our understanding of these pain problems.

Who is conducting the study?

Dr Natalie Drever is a consultant gynaecologist at Cairns Hospital and Senior Lecturer at James Cook University. She is actively involved in women’s health issues in Far North Queensland, with a particular interest in adolescent gynaecology. She has a Fellowship in Paediatric and Adolescent Gynaecology from the Royal Children’s Hospital. Professor Sonia Grover is a co-researcher. She is a leading adolescent gynaecologist who is the Director of Gynaecology at the Royal Children’s Hospital in Melbourne. Riya Gaikawaiari is a 5th year medical student at James Cook University with a keen interest in women’s health, she will be collecting and analysing data from this study, and this research project will contribute to her honours degree.

Does the project have the proper approvals?

Yes. It is approved by the James Cook University Human Research Ethics Committee. It requires informed consent from participants.

Is this project receiving any funding?

This project received a small amount of funding through James Cook University College of Medicine and Dentistry Honours project support funding. This funding will be used for any printing and postage fees, and fees associated with open access publication

Is the study anonymous?

All responses are anonymous. No personal identifiable information such as date of birth, hospital identification number or personal medical history (other than that which you provide in this survey), will be collected. Data collected will be stored in a password-protected file, only accessible to the researchers involved in this project. Importantly, your personal details, date of birth, hospital identification number and personal medical history (other than that which you provide in this survey), will NOT be accessed by the researchers, and will not be published.

What does participating in the study mean for me?

Participation in this study involves completing an anonymous online survey. This is a very quick survey, using established validated pain survey tools and questions relating to your diagnosis of MRKH, and will take up to 10 minutes of your time. You have the option of completing the survey whenever you like, in your own time, over the next 4 months. Due to the nature of the research, many women may feel that this information is

private and sensitive. Therefore, it is so important that the survey can be completed in privacy, and that it is completely anonymous – meaning no one will be able to identify you through your answers, and that any information you give through the survey cannot directly be linked to you.

If you are not able to access a digital device or stable internet, please email the research team via the contacts listed below, and we can send you a paper copy of the survey with an attached postage paid return envelope. Please ensure that your name or any other identifiable details are not on any part of the survey or the return envelope.

Can I choose to not to participate, or to withdraw from the study?

Yes. Participation is entirely voluntary, and you can choose not to participate. Volunteers are not paid for their involvement. If you choose with withdraw, it is possible to do so by exiting the browser at any point prior to your final submission of the online survey answers.

How will the results of the project be reported?

Results will be pooled together and analyzed. At completion of the project, an article will be published in a medical journal with the overall results. You will not be identified in any way in this publication. We will also ensure that a copy of the overall results of the study are provided to MRKH Australia, so you have the option of accessing their publication material to access these results.

Further questions?

If you have any questions directly about this survey, please feel free to contact the supervising researcher, Dr Natalie Drever, Natalie.Drever@jcu.edu.au. If it raises any concerns about your pain and symptoms or if you want to talk about any of the topics raised in this questionnaire, please do not hesitate to contact your General Practitioner/ 13 HEALTH/ Beyond Blue/ Lifeline about your personal health.

If you have any questions about the study, please contact **Dr Natalie Drever**.

Survey Link:

https://jcu.syd1.qualtrics.com/jfe/form/SV_6PAnc5FyL5w2DY

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If you have any concerns regarding the ethical conduct of the study, please contact:

Human Ethics, Research Office

James Cook University, Townsville, Qld, 4811

Phone: (07) 4781 5011 (ethics@jcu.edu.au)