

## **MRKH Project Qualtrics Consent Script**

### **What is the experience of pelvic and widespread pain in people with MRKH?**

#### *Survey Description*

Chronic pain conditions affect many people in the community and are reported to be present in women more often than men. There is no information regarding the experience of people with MRKH and whether their pain problems are similar, which is relevant as many pain problems vary with the menstrual cycle. Information regarding women with MRKH may be useful in our understanding of these pain problems. This is a quick survey using an established validated pain survey tool to explore your recent pain experiences. It should take up to 10 minutes of your time. This research project is being run through James Cook University, with the support of the Royal Children's Hospital, Melbourne, and MRKH Australia.

The Royal Children's Hospital is one of the major Paediatric and Adolescent Gynaecology referral centres in Australia, and cares for a large number of young women with MRKH. It has also published research in the field of MRKH and is committed to ongoing research. The results of this survey will be pooled and analysed, and the overall results may be used in a research publication in a medical journal for the purpose of improving the understanding of the wider medical community on this topic.

Participation in this project is entirely voluntary and participants are not paid for their involvement. 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.

If you would like to contact the researchers involved with this project, please email one of our investigators, Dr Natalie Drever [natalie.drever@jcu.edu.au](mailto:natalie.drever@jcu.edu.au) or Riya Gaikawaiari [riya.gaikawaiari@my.jcu.edu.au](mailto:riya.gaikawaiari@my.jcu.edu.au). If this survey 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.

By participating in this online survey, you are providing your informed consent and confirmation that you have read and understood the above. If you choose to withdraw, it is possible to do so by exiting the browser at any point prior to your final submission of the online survey answers. Please note that once you complete and submit this survey, we are unable to withdraw or alter your responses at that stage. We ask that you only complete this survey once to ensure accuracy of results.

Thank you again for your time and support.

Dr Natalie Drever and Riya Gaikawaiari.

#### **Question Title**

1. I have read the above and agree to give consent to participate in this study

Yes