



A Longitudinal Study of Health-Related Quality of Life, Body Image and Sexual Function in People Living with Gynaecological Disorders.

What is the purpose of this project?

This project is being conducted by a team of researchers at the University of Tasmania, Deakin University, University of Adelaide, Western Sydney University, McMaster University (Canada), and the NECST Network. The research is coordinated by Dr Leesa Van Niekerk, a clinical psychologist and researcher in the School of Psychological Sciences, University of Tasmania. The project focuses on health-related quality of life (HRQoL), body image and sexual satisfaction in people living with persistent and chronic gynaecological conditions such as endometriosis, adenomyosis, persistent pelvic pain (e.g., vulvodynia, interstitial cystitis), and polycystic ovary syndrome (PCOS). Our team would like to understand more about how these conditions impact on a person's overall level of emotional and physical wellbeing, their relationship with their body, and the level of sexual satisfaction they experience. The project will also gather information regarding the different physical and emotional symptoms of various persistent and chronic gynaecological conditions and the types of treatment that people may be engaged in. We are also interested in understanding whether HRQoL, body image, and sexual satisfaction differ for those living with a persistent gynaecological condition compared to those who don't.

Who is invited to participate?

Any person, assigned female at birth, aged 18 years or older, is invited to participate in this project via online surveys that are completed at a series of time intervals. The survey questions are written in the English language. We would like to hear from people living with a persistent gynaecological condition (e.g., endometriosis, adenomyosis, persistent pelvic pain, PCOS) and from those who don't.

What will I be asked to do?

If you would like to express your interest in taking part in the research, you can complete the following online expression of interest form. This will take approximately 2 minutes to fill in. The expression of interest survey will ask for your name and an e-mail address. This e-mail will be used to send you your unique survey link. It will not be used for any other purposes and is only viewable by the project coordinator, Dr Leesa Van Niekerk. You will receive a link to your unique survey 24 to 48 hours from the time of your initial expression of interest. This survey link will allow you to complete a “Baseline” survey that asks you general information about yourself such as age, gender, and country of birth, and questions about your general physical and emotional health. You will also be asked questions about how you view your body and sexual intimacy. A description of the different survey sections will be available at the start of the section and the survey has been designed so that you can save your responses and come back to complete them at any time prior to submitting your responses. Once you have completed the “Baseline” survey, we will e-mail you a link to follow-up surveys 3 months, 6 months, 12 months, and 18 months later. This will allow us to learn more about how HRQoL, body image, and sexual satisfaction vary over time.

What will you do with my personal information?

All information gathered during this study will be used for research purposes only and will be kept completely confidential. You will never be personally identified in anything published from this study. Once you have answered the online questions, you will be provided with an additional prompt that reminds you that by hitting the submit button, you are 'opting in' or providing consent for the information you have provided to be used for research purposes for the current or future research projects coordinated by Dr Van Niekerk.

Why should I participate?

Your voluntary participation will provide information that will be used to assist in understanding how persistent and chronic gynaecological conditions influence HRQoL, body image, and sexual satisfaction. Additionally, your voluntary participation will help to identify the different physical and emotional symptoms associated with a variety of gynaecological conditions and the impact of these conditions and how they may fluctuate over time. This information can be used to guide recommendations for effective treatment by medical and allied health practitioners and ultimately improve care for people living with a persistent gynaecological condition.

Participants who reside in an EU Country - General Data Protection Regulations (EU-GDPR)

The processing of personal data concerning health or personal data concerning a person's sex life or health is prohibited unless the person gives explicit consent for the processing of this personal data for a specific purpose. You can express interest in the research with no obligation to complete the online survey, change your mind about completing the survey at any stage, and withdraw your consent for your data to be used for research purposes by not submitting your completed survey responses. Once you have answered the online questions, you will be provided with an additional prompt that reminds you that by hitting the submit button, you are 'opting in' or providing consent for the information you have provided to be used for research purposes for the current or future research projects managed by Dr Van Niekerk.

Are there any possible risks to participating?

There is no significant physical risk to participating in this project, but the nature of the project means that we will be asking personal questions around sensitive topics that might result in difficult feelings. If you experience discomfort, you may wish to contact Lifeline Australia (phone: 13 11 14), or Beyondblue (phone: 1300 224 636). Alternatively, you are encouraged to make an appointment with your current mental healthcare practitioner if you have one. If you do not have a current mental health care practitioner, please speak to your GP about accessing support through avenues such as Medicare Mental Health Care Plans. If you reside outside of Australia, you may wish to contact Befrienders Worldwide at <https://www.befrienders.org/> to find a list of local support services in your area.

Freedom to refuse or withdraw.

Participation is entirely voluntary. You are free to withdraw (by stopping completion of the survey) at any time without having to explain why. If you withdraw prior to completion of the survey, your responses will not be included. Once you have submitted your survey responses, they will not be identifiable at an individual level and therefore will not be able to be deleted.

Will I hear about the results when the project is done?

Participants and supporting organisations will have access to the overall research findings. The findings will be accessible on the University of Tasmania website (www.utas.edu.au) and will be produced as publications in journals or conference presentations. You will not be personally identified in the publication of results. Any organisation that advertises the research will also be provided with a summary of the research findings to disseminate via their social media sites should

they wish to do so. A summary of the findings will also be shared on the Endometriosis Digital Platform or NECST Network.

I would like more information.

If you would like to know more about the project or have any concerns, please feel free to contact the project coordinator, Dr Leesa Van Niekerk (leesa.vanniekerk@utas.edu.au).

Concerns or complaints

This study has been approved by the University of Tasmania Human Research Ethics Committee (HREC). If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0026906.

Who are the researchers conducting this study?

Chief Investigator: Dr Leesa Van Niekerk, University of Tasmania

Investigator: Associate Professor Subhadra Evans, Deakin University

Investigator: Professor Antonina Mikoicka-Walus, Deakin University

Investigator: Dr Rebecca O'Hara, Robinson Research Institute, University of Adelaide

Investigator: Dr Mike Armour, Western Sydney University

Investigator: Dr Cecilia Ng, NECST Network

Investigator: Dr Mathew Leonardi, McMaster University

Yours sincerely,



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