



Understanding the Healthcare Needs of People Living with Pelvic Pain

## What is the purpose of the interviews?

We are conducting one-on-one interviews as part of our research exploring healthcare needs and experiences of people living with pelvic pain (e.g., endometriosis, vulvodynia, painful bladder, painful sex). We are interested to know what types of care and information you would like access to, your experience of living with pelvic pain, and how you would like your healthcare team to work with you, and each other, in managing your pelvic pain.

# Who is invited to participate?

Any woman or gender diverse person, presumed female at birth, aged 18 years or older, who lives in Australia and experiences symptoms of pelvic pain is invited to participate in the interviews. The interviewer will ask questions in English.

#### What will I be asked to do?

The first step is completing the on-line expression of interest survey below. A member of our research team will then contact you and arrange a time to complete the interview either in-person (University of Tasmania, Sandy Bay Campus), via zoom/skype, or telephone. The interview will focus on your personal experience of living with pelvic pain. Some of the questions focus on diagnosis and treatment experiences, and any things that may have made it easier or harder for you to access the type of treatment you would like. We are interested to learn what you would like your healthcare team to understand about living with pelvic pain and any preferences you may have regarding how your care team communicate with you and each other. The questions are all openended and there is no right or wrong way to answer any of them; we want to learn about your

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genuine opinions on this topic, either positive or negative. The interview will take around 30-40 minutes and can take place in person, online, or over the phone. The interview will be audio-recorded to make sure that we are correctly transcribing your responses. A few days prior to the interview, we will send you a link to some online questions that ask about your pelvic pain, your pelvic pain symptoms, and how you view pelvic pain.

## What will you do with my personal information?

All interviews will be audio recorded only and transcribed into text so that we can analyse the responses as part of this research. Any information gathered during the interviews will be used for research purposes only. Your signed consent form will be stored separately from your interview responses. Once you feel that your interview transcription is an accurate representation of our discussions, it will be stored in a way that protects your privacy. This is called a *deidentified transcript* and means that you cannot be personally identified. Before the interview starts, you will be asked to sign a consent form permitting the information you have provided to be used for research purposes for the current or future research projects managed by Dr Van Niekerk or Ms Andrews.

# **Reasons I would Consider Participating?**

Participating in an interview is an opportunity to give a more in-depth perspective on your personal experience of living with pelvic pain, which can assist us to provide recommendations for pelvic pain-related care and resources. It will also allow us to understand the treatment needs and preferences of those living with pelvic pain, from the experience of the person living with the pain, rather than from the perspective of the healthcare team.

## 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 (e.g., pain symptoms, pain experiences) that might result in difficult feelings or memories. If you experience discomfort, you may wish to contact Lifeline Australia (phone: 13 11 14) or Beyond Blue (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. You can also find a range of pelvic pain-specific resources and information at www.jeanhailes.org.au or www.endozone.com.au.

Freedom to refuse or withdraw

Participation is entirely voluntary. You are free to withdraw (by stopping completion of the

interview) at any time without having to explain why. If you withdraw prior to completion of the

interview, your responses will not be included. You will have an opportunity to review your

interview transcript for accuracy and can ask the interviewer to alter anything that is not accurate.

Once your transcript has been deidentified, it will not be identifiable at a personal level and

therefore will not be able to be deleted from the research data.

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

You can let us know if you would like to be provided with a summary of the research findings. We

will forward them to you on the email address that you provide. Alternatively, the findings will be

accessible on the University of Tasmania website (www.utas.edu.au) and will be contained in Ms

Andrew's PhD thesis and produced as publication in a journal or conference presentation. You will

be nonidentifiable in the publication of results. It is anticipated that results will be available by the

end of 2025.

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 chief investigator Dr Leesa Van Niekerk via email (leesa.vanniekerk@utas.edu.au) or PhD

researcher Cate Andrews via email (catherine.andrews@utas.edu.au).

**Concerns or complaints** 

This study has been approved by the University of Tasmania Human Research Ethics Committee. If

you have concerns or complaints about the conduct of this study, you can contact the Executive

Officer of the HREC on (03) 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

29778.

Who are the researchers conducting this study?

Chief Investigator: Dr Leesa Van Niekerk

PhD researcher: Ms Cate Andrews

Investigators: Dr Kim Jose, Dr Marie-Louise Bird