

Navigating the diagnostic process for endometriosis in Aotearoa New Zealand

INFORMATION SHEET FOR PARTICIPANTS – FOR INTERVIEWS

Tēnā koe

You are invited to take part in this research project. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Ko wai ahau / Who am I?

My name is Molly White, and I am a master's student in Health Psychology in the School of Health at Te Herenga Waka—Victoria University of Wellington. This research project is work towards my master's in health psychology

He aha te whāinga mō tēnei rangahau / What is the aim of the project?

This project will explore women and people's experiences of navigating the process of obtaining a diagnosis of endometriosis. Your participation will support this research by contributing to a better understanding of endometriosis services including any barriers to diagnosis and how these may be addressed. This research has been approved by the Te Herenga Waka—Victoria University of Wellington Human Ethics Committee [0000030903]

Ka pēhea tō āwhina mai / How can you help?

You have been invited to participate because you have identified yourself as someone who has been formally diagnosed with endometriosis in Aotearoa New Zealand and are happy to share this experience with me and are aged 16 years and over.

If you agree to take part, you will be invited to participate in an interview with me for approximately 60 minutes either in person or on-line where I will ask you questions about your experience of being diagnosed with endometriosis. I will audio record the interview with your permission and transcribe it later. I will also take notes throughout the interview. You can choose to not answer any question or stop the interview at any time, without giving a reason. The interview notes and transcript will be assigned a pseudonym, and you can supply me with this pseudonym if you wish.

You can withdraw from the study by contacting me after you have completed your interview, and up to within two weeks of reviewing the transcript from your interview once this has been sent to you. If you withdraw, the information you provided will be destroyed or returned to you.

Ka ahatia ngā kōrero ka tukuna mai / What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity, but the research data will be combined, and your identity will not be revealed in any reports, presentations, or public documentation. However, you should be aware that in small projects your identity might be obvious to others in your community.

Only my supervisors and I will read the notes and transcripts of the interview. You may view your interview transcript and make changes to it, within two weeks of receiving the transcript. You may also withdraw your data within two weeks of receiving your transcript. If you withdraw your data, it will be destroyed straight away and/or returned to you. Once analysis of data has begun, it will not be possible to withdraw your interview transcript.

The interview transcripts, summaries and any recordings will be kept securely, with printed copies locked in a file box and digital copies in a password-protected file and destroyed once my research is complete. Interviews will take place online, or at a location agreed by the researcher and interviewee if an in-person interview is requested. You may have support people or whānau present. A small gift of a \$20 Countdown voucher will be given to you to thank you for your time.

Please let me know if you would like to read a final copy of the research and I will send it to you upon completion.

He aha ngā hua o te rangahau / What will the project produce?

The information from my research will be used in my Master's Thesis, and potentially in academic publications and conference presentations.

Ki te whakaae mai koe, he aha ō mōtika hei kaitautoko i tēnei rangahau / If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you do not want to. If you do decide to participate, you have the right to:

- choose not to answer any questions;
- ask for the recorder to be turned off at any time during the interview
- withdraw from the study at any time within two weeks of receiving your interview transcript;
- ask any questions about the study at any time;
- receive a copy of your interview recording
- read over and comment on your interview transcript
- be able to read any reports of this research by emailing the researcher to request a copy.

Mehemea ngā pātai, he raruraru rānei, me whakapā ki a wai / If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either my supervisor or me:

Student: Supervisor:

Name: Molly White Name: George Parker

University email address: Molly.white@vuw.ac.nz Role: Lecturer

School: School of Health

Email: george.parker@vuw.ac.nz

He korero whakamarama mo HEC / Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may contact the Te Herenga Waka—Victoria University of Wellington HEC Convenor, Associate Professor Rhonda Shaw, by emailing hec@vuw.ac.nz.