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RESEARCH INFORMATION SHEET

Exploring the facilitators and barriers to diagnosis of endometriosis in Aotearoa New Zealand

Kia ora, my name is Briana Wallis and I am doing my Masters of Arts at Massey University. This information sheet is to give you more information so you can decide if this survey is something you might want to complete. If you have any questions, please email me or my supervisor, Kathryn (our details are at the end of this sheet).

Project Description

My research is interested in seeing what barriers and facilitators are contributing to diagnostic delays for endometriosis here in Aotearoa, New Zealand. The questions for the survey are based on the limited research from Aotearoa and internationally and will ask you to indicate what barriers you have faced on your journey to diagnosis. I also am interested in what helped you get your diagnosis. There will be chances for you to tell more of your story in open-ended questions throughout the survey.

Participant Identification and Recruitment

The study is being advertised on three endometriosis support/community group pages on Facebook, with the permission of each group's administrator. Anyone who is interested in participating in the research is invited to complete this survey. If you know anyone else who might be interested in participating, and meets the inclusion criteria, please feel free to pass the details of this survey on.

Inclusion criteria for the study include:

- Participants must be over the age of 18 years of age
- Participants must have a confirmed diagnosis of endometriosis by a gynecologist
- Participants must have received their diagnosis of endometriosis in Aotearoa New Zealand

The survey is in English.

If you participate, what will you be required to do?

If you decide to participate in this study, please complete the online survey that follows this information page. You can complete the survey in your own time, and it will take approximately 20-30 minutes to complete. The survey will be open until 31 July, 2022.

The survey consists of five sections which ask questions about your background information (demographics), journey to diagnosis, facilitators and barriers to the diagnosis of endometriosis which occur at the individual, medical and societal levels. Your identity will remain anonymous, and you will only be known as a participant number. However, if you would like to go into the draw to win a \$100 Prezi card, you will be asked for an email address at the end of the survey. This will be stored separately to your other survey answers.

As you complete the survey, your progress will be automatically saved, meaning you do not have to finish the survey in one sitting, and can take time to think about how you would like to answer any of the questions

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You are free to withdraw from the study at any time. To do this, simply close your browser window the survey is presented on without submitting your responses. While your progress will be automatically saved, your responses will not be recorded, and your progress will be deleted when the survey closes.

Risks and Benefits

It is not anticipated that involvement in this study will involve any risks or discomfort to participants. In fact I hope this research will give us a unique perspective to the barriers and facilitators to diagnosis here in Aotearoa. However, due to the challenges of living with endometriosis, we know that it may be difficult to share some aspects of your journey and it is possible that this may be an emotional experience. As such, there is no pressure to share anything you do not want to. If you do not feel comfortable responding to a question or feel the question is irrelevant to your journey, you can either leave the answer field blank or select the 'not applicable' option. I have included a list of free supports available and I encourage you to utilize your own support networks:

- Endometriosis New Zealand – <http://nzendo.org.nz/helping-you/>
- Need to talk? - free call or text 1737 any time for support from a trained counsellor
- Lifeline Aotearoa – 0800 543 354 (0800 LIFELINE) or free text 4375
- Healthline – 0800 611 116
- Suicide Crisis Helpline – 0508 828 865 (0508 TAUTOKO)

Data Management

All personal information and data collected during this study will be stored securely on a password-protected network that only myself, the researcher, and my supervisor, Dr Kathryn McGuigan, will be able to access. All data will be destroyed once the project is completed in February 2023. I will be responsible for making sure that your data will only be used for the purposes mentioned in this information sheet.

Participants' Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Withdraw from the study up until you submit your responses;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used;
- Be given access to a summary of the project's findings when it is concluded.

Thank you for taking the time to enquire about this project and to read this information sheet. We greatly appreciate your consideration of this invitation, and we welcome your participation in this study. If you have any questions about the project, please do not hesitate to reach out to either myself, or my supervisor, Dr Kathryn McGuigan, at the details below.

Researcher: Briana Wallis

Supervisor: Dr Kathryn McGuigan

Email: Briana.Wallis.1@uni.massey.ac.nz

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Statement of Ethical Approval

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Prof Craig Johnson, Director, Research Ethics, telephone 06 356 9099 x 85271, email humanethics@massey.ac.nz.