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**The Perspectives, Experiences and Priorities of Māori and Pasifika Endometriosis (mate kirikōpū) Patients
in Aotearoa New Zealand
Information Sheet for Participants**

Kia ora,

You are invited to participate in a research study on the experience and priorities of Māori and Pasifika New Zealanders that have endometriosis. This study is being conducted by Katie Ellis from the University of Canterbury | Te Whare Wānanga o Waitaha (UC). Other research team members include Dr Deborah Munro, Dr Rachael Wood and Dr Jordan Tewhaiti Smith (Ngāti Kahugunu, Ngāi Tahu, Ngā Puhī). The study is being carried out as a part of a research into endometriosis for a PhD.

The questions and discussions will cover your experiences with endometriosis including symptoms, your journey to diagnosis, misdiagnoses, treatments and what you would like see done in endometriosis research in Aotearoa New Zealand. To participate you must be over the age of 18 and reside in Aotearoa New Zealand with a working diagnosis of endometriosis from your GP or OBGYN, or a confirmed diagnosis from surgery.

What is the purpose of this research?

This research aims to determine the perspectives and experiences of endometriosis patients in Aotearoa New Zealand. This research would also like to evaluate the priorities of endometriosis patients, so that emphasis can be placed on completing the research they would most like to see done for their condition. We are further interested in learning about the feelings endometriosis patients may have about current methods of diagnosis and treatment and the effects of delays, costs and culture on their ability to access diagnosis and treatment. The information from this study will help enhance our research team's understanding of the needs of patients and will be used in our research priorities to ensure the lived experiences of patients are at the forefront of our work.

Why have you received this invitation?

You are invited to participate in this research because you have indicated you have a working diagnosis or surgically confirmed diagnosis of endometriosis. Your participation is strictly voluntary (your choice). If you decide not to participate or withdraw, there are no consequences. Your decision will not affect your relationship with the University of Canterbury or any member of the research team.

What is involved in participating?

If you choose to be part of this research, you will be asked to participate in an online discussion-based focus group. There will be up to thirty people in each focus group. This focus group will involve you logging in multiple times within a five-day window to provide written answers to questions and interact and respond to the written responses of other participants. There will be up to thirty people in the discussion. The focus group will take place online on a platform called VisionsLive, and you will be emailed a link specific to you.

Your identity will not be revealed in the focus group, and you will be assigned a pseudonym by which you will be known to other participants.

There will be set questions consisting of single and multiple-choice polls and longer answer open questions. Once you have answered a set of questions, you will then see other participants' responses. You will be able to respond to their comments to facilitate group interactions. Katie Ellis, a member of the research team moderating the discussion, may also respond or engage you with further questions based on the group's responses. The moderator will closely monitor the discussion and has the option of responding directly to a respondent individually, as well as the option to delete any inappropriate comments. Answering all the questions and responding to the comments of other participants is estimated to take approximately 120 minutes. This time can be split into as many intervals as you want to complete all the questions within the five-day window. If you are unable to complete the questions within the five-day window but still want to respond to them, please contact Katie Ellis and you can receive a manual copy of the questions.

The discussion group is entirely anonymous. All participants have pseudonyms such as Daffodil or Blue. As the discussion is in written format only, all of your personal identifying information, including your face, voice, and other identifying features, will remain private. The research team may, at their discretion, edit responses to remove any potentially identifying information both during the five-day window or after the discussion forum is complete.

Will the focus group be recorded?

A transcript of the online discussion focus group will be kept. All researchers will sign a confidentiality agreement before reading the anonymised transcript. Your identifying information will be kept on a secure university server separate from the transcript.

Are there any potential benefits from taking part in this research?

Participants in online discussion board focus groups report enjoying the opportunity to discuss topics in a safe, anonymous pace. You also have the potential opportunity to learn more about the experiences of others who are navigating endometriosis. You will also have the opportunity to influence the direction of future research to better meet their needs.

All participants that complete all of the set questions will receive a \$20 online voucher, to use at a retailer of your choice from a list. The funding for this voucher comes from the Biomolecular Interaction Centre which has funded this research endeavour.

Are there any potential risks involved in this research?

Some questions or topics discussed may involve sensitive information about the experience of endometriosis, which is a chronic pain condition that can holistically impact the lives of those who have it. This may cause you to become upset or distressed. If you become upset or distressed, we can help you decide whether or not you wish to proceed, or you may withdraw from the study without providing any reason. We can also talk you through other ways to participate in the study (such as completing the discussion questions offline).

We have worked to limit the risk of cross-cultural miscommunication by ensuring all questions have been checked by both Māori and Pasifika researchers and clinicians. Katie Ellis the moderator is Paheka, but will be in discussion with the Māori and Pasifika collaborators to ensure that no follow-up questions are unintentionally culturally insensitive.

In the event you experience any distress, feel free to reach out to any following services for support or guidance.

- LIFELINE – 0800 543 354 or text HELP to 4357 for free, 24/7
- All Right? – Free call or text 1737 any time, 24 hours a day
- Healthline – For general health advice and information call 0800 611 116
- Youthline – Free call 0800 376 633 or text 234
- For more information about endometriosis, look up Endometriosis New Zealand at <https://nzendo.org.nz/>

What if you change your mind during or after the study?

You are at liberty to withdraw at any time. To do this, please feel free to leave the group at any point or let the researchers know that you wish to withdraw. If you wish to have your responses withdrawn, we will remove any information you have provided. If you choose to withdraw after the discussion board has closed, if it is still possible within a week of the discussion board closing, the researchers will make every effort to remove your contribution. Please note that the nature of focus group discussions makes it difficult to remove data or the influence of your contribution. However, every effort will be made to do so.

What will happen to the information you provide?

We will ask each online discussion focus group participant to agree not to share information with people outside the focus group. If you are unable to agree to this, you will not be able to participate. All the researchers will keep your identity and information provided during the focus group confidential. To ensure your identity is not known to anyone outside the research team, we will store signed consent forms separately from the focus group transcript and notes. Only the pseudonym used during the discussion will appear in the transcript. Any quotes used while presenting the results will not be connected to any identifying information. We will store the file that links your real name to your pseudonym on a password-protected, secure device. All study data will be stored in password-protected files on the University of Canterbury computer network, stored in lockable cabinets or on a password-protected USB.

All data will be kept up to ten years. Katie Ellis will be responsible for ensuring that your data is only used by members of the research team for the purposes mentioned in this information sheet. Upon completion of her doctoral thesis, or if Katie Ellis decides to discontinue this research endeavour, responsibility for the transcripts and research data will be transferred to Dr Deborah Munro.

How will the results of the study be published?

The results of this research will be published in a doctoral thesis. This thesis would be available to the general public through the UC library. Results may be published in peer-reviewed, academic journals. Results will also be presented during conferences or seminars to wider professional and academic communities. You will not be identifiable in any publication.

Katie Ellis will send a summary of the research to you at the end of the study, if you request this.

Who can you contact if you have any questions or concerns?

If you have any questions about the research, please contact: Katie Ellis: khe71@uclive.ac.nz; Dr Deborah Munro: debbie.munro@canterbury.ac.nz; Dr Rachael Wood: rachael.wood@canterbury.ac.nz

This study has been reviewed and approved by the University of Canterbury Human Research Ethics Committee (HREC). If you have a complaint about this research, please contact the Chair of the HREC at human-ethics@canterbury.ac.nz.

What happens next?

Please review the consent form. If you would like to participate, please sign, scan/take a photo of, and return the consent form to Katie Ellis at khe71@uclive.ac.nz.