Project Title: The Invisibility of Mothering with Chronic Illness: Embodied Relationships, Entangled Feelings

INFORMATION SHEET FOR PARTICIPANTS

Kia ora. This information sheet will tell you about this research project and how you may wish to be involved. Te reo Māori kupu (words) will be used for common phrases throughout this information sheet such as whānau (family), tamariki (children), tamaiti (child), kōrero (conversations or interviews), and māmā (mothers). This research has been approved by Te Herenga Waka—Victoria University of Wellington Human Ethics Committee (HE040024).

Ko wai ngā kairangahau? / Who's in the research team?

This project is a collaboration between Chloe Parton (Pākehā, she/her), Fran Kewene (Waikato, Ngāti Maniapoto; Ia), Gareth Treharne (Welsh, Pākehā; he/him), and Martine Matapo-Kolisko (Titikaveka; she/her). Chloe, Fran and Martine are based at T*e Puna Hauora – School of Health, Te Herenga Waka – Victoria University of Wellington*. Gareth is based at *Te Tari Whakamātau Hinekaro - Department of Psychology, Ōtākou Whakaihu Waka - University of Otago.*

He aha te whāinga o te rangahau nei? / What is the aim of the project?

We want to better understand what it is like to be a māmā of young tamariki (0-5 years) while living with rheumatoid arthritis. This research explores how māmā experiences their relationships with their tamariki and whānau, and how they manage their own health needs. We hope the findings will be used to help support māmā with rheumatoid arthritis and make things easier for them and their whānau.

Kei ā wai ngā kōrero matua? / Who do we want to talk to?

We want to kōrero with māmā (16 years or over) who have a diagnosis of rheumatoid arthritis, a tamaiti or tamariki of five years or under and who would like to share their experiences and insights with us.

There are lots of ways to be a māmā. We are interested in speaking to people who identify with being a māmā, regardless of their gender identity (i.e. non-binary and trans people), or pathway to being a māmā (i.e. māmā in same-sex relationships, whāngai, adoption, blended whānau). You do not need to have biological tamariki.

Mēnā ka kuhu mai koe, he aha ngā āhuatanga o te kaupapa nei? / What is involved if you decide to take part?

Kōrero will be in person *or* through Zoom (online video conferencing) if that is your preference. If you live outside of the Wellington region and would like an in-person kōrero , we will try our best to organise travel to visit you. There are three stages to our research:

1. The first kōrero will prioritise whakawhanaungatanga and relationship building, while asking some questions around your experience of being a māmā with young tamariki who has rheumatoid arthritis. This might include things like what was becoming a māmā like for you? What is it like having rheumatoid arthritis as a māmā? What things make it more challenging? What things help you? Who supports you and makes things easier for you?

2. After the first kōrero, we will ask if you would like to take part in a photography exercise with a phone or camera (we can help you if you don't have a working camera or prepaid data). This photography exercise can be entirely led by you. You will photos of what is important to you as a māmā in your daily life over a three-week period. We can have a conversation as part of our first kōrero to come up with some ideas about what you might like to focus on to get you started.
3. In the second and final kōrero, we will discuss your photos as well as any other reflections that you might have. You only need to share photos that you feel comfortable sharing. There may be some photos you do not wish to share. You can decide if these photographs are used just with the research team, or when publishing the research and sharing the findings. Whatever you decide to do, it's important you do what you feel most comfortable with and what works for you and your whānau.

During all kōrero the researchers will ask open-ended questions to encourage discussion and guide the conversation. Questions that will be asked during the kōrero have been prepared in advance. The ethics committee have seen these questions, but additional questions may be asked depending on how the kōrero unfolds. You are welcome to decline answering any questions or end a kōrero early. We will remind you of this during the kōrero and if you do decide to end early or skip a question, we won't ask you why. You are also welcome to talk about things that we haven't asked you about that would help us understand what it is like for you as a māmā.

We expect that each kōrero will take 60-90 minutes. We will offer you a $40 voucher to recognise your time, wisdom and valued matauranga after each kōrero and the photography exercise. We would also like to offer you copies of your stories from the kōrero and photographs, if you would like this. These stories and photographs are a taonga, and you might like to think about whether you want to hold on to these for you or your whānau – it's up to you. If you do decide you might like to hold onto these, we will also give you some information to think about how you can best store and look after your taonga.

He aha ngā kohikohinga rangahau, otirā he aha te hua o ngā raraunga? / What data or information will be collected and how will it be used?

All kōrero will be voice-recorded through a dictaphone. If the kōrero takes place over Zoom, then the video-call will be recorded. All kōrero will be transcribed using Microsoft Office Copilot.

The interview transcripts and the photographs taken will be used to identify patterns relating to māmā experiences while living with rheumatoid arthritis across all the participants in the study.

We will keep your contact details to stay in touch with you during the project If you wish to opt out of project updates, let the researchers know at your convenience. When the project has finished, your your contact details will be deleted, unless you have given permission to be contacted about future research

Generally, we report contributions from participants in research publications anonymously, but you can choose to have your opinions recognised and attributed to you if that is your preference, and you can indicate this on the consent form. It's important to note that if you do choose to be identified, this may mean that your tamariki may also be identified by association when we publish the results.

Oranga tonutanga tamariki, māmā, whānau hoki. / Child, mother and family wellbeing

He taonga ngā mokopuna
Our mokopuna are treasures

Tamariki, māmā and whānau are precious taonga and this within the kaupapa of our project. We encourage you to check in with your whānau, including tamariki, to see if they are happy to be part of any pictures you take. For example, this could mean saying to your tamaiti, "I'm taking pictures of what my life is like as a mum for people who want to learn about me. Would you like to be in one? It's okay if you don't." Tamariki who may not be able to speak yet, or who may be feeling unsure might tell us that they are not feeling comfortable through their bodies (turning away, doing something else). It's

okay if tamariki don't want to be in photographs. Your photos are still important and valuable to the study, whatever you choose to focus on.

If you want to include your whānau who are adults or young people (i.e. 16 years or older), check in with them as well to make sure they are okay with being included in the photographs. If you decided that you would like to give one of these photographs to the researchers to be included in the study we might check in with your whānau member to see if they are willing to give written or audio-recorded consent to have their photo included in this study. This is their choice. If they choose not to, we won't use any of their images in the research we publish or share with the public.

Remember, it's up to you which photos you choose to share with us as researchers as well. Some photos you may want to kōrero about with us. Others, you may wish for us to directly include in the research – it's up to you. Whatever you share with us, your stories and photographs are a taonga within this research.

Finally, it's important to respect and care for whānau. Everything you tell us stays between us. The only exception to this is if you let us know that it is possible that you or your tamariki are not safe (i.e. there is the possibility of someone being seriously hurt). In this case, we will reach out to the right people to ensure that your whānau receives support.

Mēnā ka huri te tai ō whakaaro e pai ana kia wehe i te kaupapa? / Can participants change their mind and withdraw from the project?

If you change your mind about being involved during the kōrero, then you are free to leave at any time. After both kōrero are complete, you have up to one month to withdraw from the study. If you withdraw from an interview or the photography exercise before they are finished you'll still receive a voucher for that activity. After this time, you will not be able to withdraw your data from the project (e.g., if an article has been published).

He whakaaro ōu? Tēnā whakapā mai. / If you want to get in touch with us

If you have any questions about our project, either now or in the future, please feel free to contact any of the researchers below:

Primary Investigator: Chloe Parton

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Associate Investigator: Fran Kewene

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He kōrero whakamārama mō HEC / Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may raise this with the HEC Convenor, Te Herenga Waka—Victoria University of Wellington, by emailing human-ethics@vuw.ac.nz or phoning the University's Service Centre on 0800 04 04 04.