A cooperative inquiry project to understand how women with rheumatoid arthritis navigate perimenopause

Participant Information Sheet

Thank you for your interest in this project. The information below summarises the research and describes what being a participant will mean for you.

It is important that you understand what the project is about so if you have any questions or would like to speak to me, please use the contact details at the end of this document

About the Project

Rheumatoid arthritis (RA) affects around 2.5 percent of the population in Aotearoa New Zealand and occurs 3 times more frequently in women than men. Most women are diagnosed with RA in their 40s to 50s which is around the same time they experience perimenopause. Perimenopause is the transition to menopause when hormone levels decline and symptoms like hot flushes and irregular periods start. Perimenopause and RA each bring significant challenges, but when they occur together, we know little about the combined experience or effective ways to manage it.

We want to know about your experiences of going through perimenopause with rheumatoid arthritis – how it affects your life, your body, how you think about yourself and what you do to cope. I am interested in what happens when I bring a group of similar people together to explore what going through perimenopause with rheumatoid arthritis is like. Does thinking together help people find ways of coping better? I hope that this will be a fun and interesting experience for those who participate in this project, and that our findings will help people with rheumatoid arthritis during this transitional life stage.

About the researcher

My name is Jo Miller. I am a master's student at Massey University studying health psychology and this research is for my thesis requirements. I have a particular interest in women's health and ageing and have been on placement at Arthritis NZ exploring menopause and arthritis. I recently led a workshop with women to explore the link between menopause and arthritis. The discussion showed that women with arthritis are really interested in how menopause has impacted their quality of life.

Who Can Take Part?

To take part in this study you must meet the following criteria:

- Have a diagnosis of rheumatoid arthritis
- Aged over 40 with irregular periods and/or menopausal symptoms
- Or aged under 40 and have gone through spontaneous early menopause

I am especially keen to hear the perspectives of people who are often left out of research, including:

- sexually or gender diverse/takatāpui
- ethnic minorities
- Indigenous women/wāhine Māori
- women of colour

What's Involved?

If you participate in the study, I will include you in a group of 3-4 people. You can ask to be put in a group, or you can suggest an existing group, such as a group of your friends.

The group will meet face-to-face or virtually on Zoom/Teams fortnightly for up to 3 meetings, depending on your preference. Together we will reflect on your experiences, what you do to cope, and what could be done differently. I will do this through discussion/kōrero and activities designed to help creative thinking. For example, we may use care-full conversations (health cards) to prompt discussion.

The groups are called cooperative inquiry, because through group discussion people identify aspects of their experiences they want to understand better or differently – that they want to "inquire into". During the group meetings we discuss your experiences, and in-between meetings you do a small activity related to your inquiry. For example, this might mean noticing something, or perhaps doing something different and seeing how that makes you feel. This means that participating in the project will require a small amount of time outside of the meetings.

What Happens to the Information?

The meetings will be audio recorded and transcribed (typed up). I will send you these transcripts, and you will have the opportunity to read them and amend them. For example you may want to add more information for clarification or ask me to delete something you've said. You will have two weeks to do this, after which you will not be able to withdraw or change your data.

All information will be kept on a password protected laptop and backed up using password protected secure cloud space. Only myself and my supervisor will have access to the recordings and transcripts. The transcripts will be anonymized which means removing all information that could identify you. At the end of the research, the audio recordings and anonymised transcripts are kept in a secure location for five years before being destroyed, in accordance with Massey University policy.

Participant Rights

You can withdraw from the inquiry group at any time before the group begins or while the group is in progress. You can ask for your talk to be removed from the transcripts, but it will not be possible to withdraw the information you provide after the group finishes, as it will be part of a discussion with other participants. The information you provide will be on the understanding that your name will not be used in research outputs

A summary of findings will be given to all participants, this will also contain links to the published thesis. The findings of this research will also be shared with Arthritis NZ, a national charity that provides information, advice and support to people living with joint pain and those diagnosed with any of the more than 140 forms of arthritis.

Risks and Benefits

It is not expected that this research will cause harm/risk to you, and we hope it will be a fun, enjoyable and interesting process. But talking about menopause may be awkward. We will try to make participating in this study as easy as possible by giving group members permission to feel awkward, working with friendship groups and using activities to get to know each other so that we can work through any awkward feelings quickly, and focusing on the experience rather than explicitly studying menopause.

Each group will also discuss their own ground rules, and revisit these during the project to check they are working or if they need tweaking. These will include what we do if someone in the group becomes upset or has strong feelings as they reflect on their experiences.

If you find any area of the process to be uncomfortable, you can choose not to take part. As the researcher, I will be available to discuss any concerns you have throughout the project and I will have contact numbers available for you if you wish to seek professional support.

The nature of research in small groups involves discussions/ kōrero with other participants. We will ask group members to keep what is said in the group confidential, but we cannot guarantee this. So

there is a risk that other group participants might disclose your involvement, identity or what you say to others in the focus group. Taking part in the project means that you are willing to accept this risk. If you change your mind, you can leave the group at any time.

The research is intended to have the following benefits:

1. The cooperative inquiry group method supports participants to define and inquire into what matters to them, and can give them new, more affirmative ways of thinking.
2. Insights from participants will be written up in academic publications and may impact on future research and support for women with RA going through perimenopause.
3. Findings will be shared with Arthritis NZ to develop resources such as fact sheets, articles, webinars, workshops, and information for MyRA, a resource that helps people become active participants in their journey with RA.

A voucher of $20 per meeting will be given to each participant as a token of appreciation.

Project Contacts

Researcher
Jo Miller
School of Psychology
Massey University
Wellington
Email: Jo.Miller.3@uni.massey.ac.nz
Telephone: 021 221 5171

Supervisor
Professor Sarah Riley
School of Psychology
Massey University
Wellington
Email: S.Riley@massey.ac.nz

What's Next?

If you would like to take part in the study or have a chat with the researcher, please contact Jo by email, text or phone using the above details.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/34. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email humanethicsnorth@massey.ac.nz.