Department of Psychological Medicine
Faculty of Medical and Health Sciences
The University of Auckland
Auckland 1142, New Zealand
Private Bag 92019

PARTICIPANT INFORMATION SHEET

Title: Experiences of People with Rheumatoid Arthritis

Researchers: Professor Keith Petrie, Michelle Taylorson (Doctoral candidate), Professor Nicola Dalbeth (Rheumatology Specialist).

You are invited to take part in a study exploring the experiences of people with rheumatoid arthritis (RA). Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive.

This Participant Information Sheet will help you confirm that you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. Before you decide, you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, completing the anonymous survey will be considered your informed consent. Because all your responses are anonymous, it will not be possible to withdraw your data from the study after you have completed and submitted the survey. This Participant Information Sheet is downloadable for you to keep.

WHAT IS THE PURPOSE OF THE STUDY?

You have been invited to participate in this study because you have been diagnosed with rheumatoid arthritis, and you have been prescribed medication to help manage it. Participation is voluntary. The aim of the study is to understand more about the different beliefs people with RA may hold about their body and whether these relate to the behaviours, activities and experiences of patients.

You are eligible to participate if you have a confirmed diagnosis of RA, are receiving treatment for your RA, are over 18, and are able to complete online questionnaires in English.

This study is funded by the Faculty of Medical and Health Sciences at the University of Auckland as part of a Doctorate in Health Psychology. For questions, please contact Professor Keith Petrie (contact details on page 3) or student researcher Michelle Taylorson (mtay322@aucklanduni.ac.nz).

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

Taking part in this study will involve completing one online survey. The survey should take no more than about 15-25 minutes to complete.

The survey will be anonymous and asks about your RA diagnosis and treatment, your beliefs about your body in the context of RA, how RA impacts your daily life and physical activity, your medication and healthcare, your general wellbeing, and some background information about you.

Your involvement in the study will contribute to our understanding of how we can enhance communication and outcomes for RA patients.

We encourage you to discuss your involvement in the study with whānau before consenting to the study, should you wish to do so.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

Researchers do not expect you to experience any kind of risk from completing the survey. The treatment you are receiving from your rheumatologist or other medical care team will not be affected in any way by your choice to participate or to not participate in this research.

If you have any concerns about your RA during or after completing the survey and are not sure who to talk to, you can try calling:

- Healthline 0800 611 116
- Arthritis Assist 0800 663 463
- For emergencies, contact Emergency Services by calling 111

WHO PAYS FOR THE STUDY?

You will not incur any financial costs due to participation in this study.

To thank you for your time, you'll have the opportunity to enter a draw to win a $200 shopping voucher at the completion of the survey.

WHAT ARE MY RIGHTS?

Participation in this study is completely voluntary.
If you choose to take part, you can leave the survey at any time before you have completed it, without giving a reason.
Please note that once you have submitted the survey, it will not be possible to withdraw your data as your responses are completely anonymous and cannot be identified.
Whether or not you participate in this study will not affect your relationship with your healthcare provider or your future health care.
You can download a copy of this document to keep.
You can ask questions about the study and can contact the student researcher Michelle Taylorson or co-researchers of this project through their details at the bottom of this sheet.
The survey is fully anonymous. No identifying information is collected as part of your survey responses.
Only the researcher and supervisor will have access to the study data.
If you choose to enter the prize draw or receive a summary of the study results, you will be redirected via a separate link at the end of the survey to provide your name and email address. This contact information is stored in a separate data file from your survey responses, with no link between the two. Your contact details will be used solely for prize draw administration and dissemination of results, and will be permanently deleted once these have been completed.

Publications and presentations on the study will not contain any information that could identify you.
Ethnicity data will be collected and recorded in line with the Ministry of Health ethnicity data protocol, and Māori organisations will be able to request access to de-identified study data, for uses that may benefit Māori.
A de-identified data-set will be created for the possibility of fulfilling the requirements for publication of the results in a peer-reviewed scientific journal and is the only foreseen instance that data would be sent overseas or to another institution.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Because the survey is completely anonymous, it is not possible to withdraw your data once you have submitted it, as your responses cannot be identified. You can choose to leave the survey at any time before submitting it by closing your browser.

A summary of the results of this study will be sent to you if you have indicated this at the end of the survey. As it takes time to analyse the data, it can take more than a year after participation for the summary of the results to be sent to you.

All anonymous survey data will be stored securely on Qualtrics, an online platform using high quality security protocols, and on the University of Auckland's secure server. Data will be stored for six years, after which it will be permanently deleted. The de-identified dataset and some other documents may be shared on an open science platform as part of the publication process.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Keith Petrie
Professor of Health Psychology
Department of Psychological Medicine
The University of Auckland
Private Bag 92019
Auckland 1142
(09) 923 6564
kj.petrie@auckland.ac.nz

Michelle Taylorson
Doctoral Candidate
Department of Psychological Medicine
The University of Auckland
Private Bag 92019
Auckland 1142
021 230 8053
mtay322@aucklanduni.ac.nz

Professor Nicola Dalbeth
Department of Medicine
Faculty of Medical and Health Sciences
School of Medicine
University of Auckland
n.dalbeth@auckland.ac.nz

If you require Māori cultural support you may contact He Kamaka Waiora (Māori Health Team) by telephoning (09) 307 4949, extension 29400. Or by emailing hkw@adhb.govt.nz. For any concerns regarding ethical issues you may contact the Chair, the Auckland Health Research Ethics Committee, at the University of Auckland Research Office. Email: ahrec@auckland.ac.nz.

Approved by the Auckland Health Research Ethics Committee on [Date] for three years. Reference Number [Number].