



## **PARTICIPANT INFORMATION SHEET**

### **Experiences of Inflammatory Arthritis Study**

Principal Investigator: Professor Keith Petrie  
Student Researchers: Rachael Yelder & Chiara Gasteiger  
Co-Investigators: Professor Nicola Dalbeth & Meihana Douglas  
2021

You are invited to take part in a study examining people's experience of living with inflammatory arthritis in New Zealand.

### **Researcher introduction**

This study is being carried out by Rachael Yelder, a student researcher from the Department of Psychological Medicine, and Professor Keith Petrie (Psychological Medicine), who is supervising the project.

### **Project description and invitation**

The likelihood of being diagnosed with a form of inflammatory arthritis is increasing. You are invited to participate in a study investigating the experience of people already living with inflammatory arthritis. This study is aiming to recruit sixty people diagnosed with rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis to investigate the similarities and differences between living with each condition. This letter contains an overview of this study to help you make an informed decision as to whether you would like to participate in this research.

### **Procedure**

If you are eligible and choose to participate in this study you will be asked to complete an online survey (approximately 10-minutes). This survey will ask you some questions about your demographics and your inflammatory arthritis condition. You will also be asked about your thoughts and experience of living with your inflammatory arthritis. It is important to know that there are no wrong answers – the right answer is the one that is true for you. Your answers will not affect your future healthcare.

To thank participants for their contribution to the research, you will be given the opportunity to enter a prize draw to win one of two \$100 shopping vouchers. If you choose to enter the prize draw, wish to receive a summary of the results, and/or wish to be contacted about future research, you will be asked to provide your name and an email address on a separate form. Any personal details you provide will be stored separately to your questionnaire responses (which will remain anonymous).

### **Eligibility**

To take part in this research you must be 18 years of age or older, be able to read and write in English and be living in New Zealand. You must also have a diagnosis of rheumatoid arthritis, psoriatic arthritis, or ankylosing spondylitis.

**Your rights as a participant**

Participation in the study is entirely voluntary. If you choose to participate, you can change your mind at any time, without any negative consequences, by not submitting the questionnaire. By submitting the questionnaire you are confirming that you have understood the information provided about the study, are satisfied with the response you have received to any questions you may have, and you consent to participate in the research.

**Risks and discomforts**

There are no expected risks or discomforts associated with this study.

**Data storage**

All data will be stored by the researcher in electronic format: in a password protected data file on a University of Auckland computer. Data will be kept for a period of six years.

**Confidentiality**

This questionnaire is anonymous meaning that your identity will not be linked to your response. If you choose to give your name and email address in order to receive a summary of results, enter the draw to win a shopping voucher, or to be contacted about future research, these details will be separate from your questionnaire response. All personal information will remain confidential and no material that could personally identify you will be used in any report on this study. After completion of the study, all data files will be stored for a minimum period of six years to allow for publication and re-analysis, after which time it will be securely and confidentially disposed of. Research publications and presentations from the study will not contain any information that could identify you.

**Results**

You will be given the option of requesting a summary of the results of this study. If you select that you would like to receive a summary, it will be sent to you via email once the study has been completed. As it takes some time to analyse the results of studies, it may be more than a year after your participation that you receive this information.

**We appreciate the time you have taken to read this information. If you have any questions please contact:**

**Rachael Yelder:**

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Professor Trecia Wouldes, Department of Psychological Medicine  
The University of Auckland. Email: [t.wouldes@auckland.ac.nz](mailto:t.wouldes@auckland.ac.nz)

**Māori Cultural Support:**

If you require Māori cultural support, talk to your whānau in the first instance.  
Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

If you have any questions or complaints about the study, you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext 3204.

**AHREC Chair contact details:**

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at [ahrec@auckland.ac.nz](mailto:ahrec@auckland.ac.nz) or at 373 7599 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142

Approved by the Auckland Health Research Ethics Committee on 19/07/2021 for three years.  
Reference number 22869.