

Participant Information Sheet

Date Information Sheet Produced: 21st September 2023

The experiences and perceptions of gout flares and physical activity in people with gout

Kia ora

Kia ora, Ko Kōtirana te whakapaparanga mai, engari, Ko Tāmaki Makaurau te whenua tupu. Ko Te Motu Waiheke te kāinga. He Kaiwhakaako au i Te Wānanga Aronui o Tāmaki Makau Rau. Ko Sarah Stewart taku ingoa.

My name is Sarah Stewart. I am a researcher at the Auckland University of Technology. I am working with Libby Anderson (Ngati Maniopoto-Waikato), Professor Tania Ka'ai (Ngāti Porou, Ngāi Tahu), Dr Irene Zeng, Professor Nicola Dalbeth, Associate Professor David Rice, Professor Nicola Kayes, and Dr Julie Collis. We are interested in exploring the experiences of people with gout about physical activity and would like to invite you to participate in an interview study. This research is being funded by the Health Research Council of New Zealand.

What is the purpose of this research?

Gout (mate waikawa kai kōiwi) is a common form of arthritis. Gout can cause sudden attacks (flare-ups) of pain and swelling. Some people with gout have identified excessive physical activity as being a trigger for their gout attacks and avoid being physically active for fear of triggering an attack. The pain of a gout attack also prevents people with gout from being physically active. This poses an important problem, because 'regular exercise' is recommended for people with gout to improve overall health. As part of this research, we will be interviewing people with gout to better understand their experiences of physical activity. You do not have to consider yourself to be an active person to participate in this study. Physical activity includes activities that you might do at work, part of your house and yard work, to get from place to place, as well as what you might do in your spare time for recreation and exercise or sports.

The findings of this research may be used for academic publications and presentations and will be used to develop physical activity guidelines for people with gout.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate in this research because you have responded to an advertisement you have seen. To be eligible to participate, you must be living in Aotearoa New Zealand, have gout diagnosed by a doctor, and be aged 20 years or older.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. If you choose to participate, you will need to complete a Consent Form (attached to the end page of this document). The consent form can be completed in-person, just before your interview, or if you choose to do your interview online via Zoom, or over the phone, the researcher will gain your consent orally before the interview starts. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

If you agree to participate, you will be invited to take part in a single interview with Sarah (AUT researcher) and/or Libby (AUT research student). You can choose to do the interview in person at your own home, at a local library or café, or at our AUT North Campus (located in Northcote, Auckland) or AUT South Campus (located in Manukau, Auckland). Alternatively, if travel is difficult for you, or you live out of Auckland, we can do the interview online via Zoom or over the phone. The interview will take no more than 60 minutes. The interview will be a conversation about your experiences of physical activity and gout. During the interview, we will ask you some questions and give you plenty of time to your story and your experiences. Please remember that we don't know anything about your experiences of physical activity and gout, so anything you share is really valuable in helping us to understand this. There are no right or wrong answers to our questions. You are welcome to bring a support person/member of your

whānau with you to the interview. If you do not wish to answer a particular question or continue with the interview, you will be free to stop at any time without giving a reason. You will be offered an opportunity to review the audio recording transcripts of your interview. You will be given the option to review these via email/post or discussing these online via zoom, over the phone, or in person, which will take place 3 to 4 months after the initial interview. If you do wish to review your transcripts, please indicate so on the relevant section of the Consent Form. At the end of the interview, you will also be asked to complete a short questionnaire about any physical activity you have done over the past week.

What are the discomforts and risks and how will they be alleviated?

It is not expected that participation in this study will cause any discomfort or risk. However, it is possible that you will be emotionally affected if you are recalling your past experiences of gout flares. If this were to happen, you will be given additional time, and the option of not answering a particular question or discontinuing the interview. You do not need to give a reason why.

AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9292.
- let the receptionist know that you are a research participant and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

What are the benefits?

Participation in this study will provide you with the opportunity to share your story. The knowledge we gain from hearing your story will be of benefit to other people with gout as well as to doctors to better support people with gout in maintaining regular physical activity. This information may be used to guide the development of gout-specific physical activity guidelines with the overall goal of reducing gout attacks, while also achieving physical fitness and managing overall health.

How will my privacy be protected?

Sarah and Libby will be audio recording your interview so that they can transcribe it later (write it down word-for-word). To protect your confidentiality, no real names or other identifiable information will be used in the transcriptions. Your identity will never be revealed in any publications or presentation arising from this study. Apart from the study researchers, no one else will have access to your information. All data, including Consent Forms, will be kept secure on AUT premises and destroyed six years after completion of the study.

What are the costs of participating in this research?

The only cost to you will be up to 60 minutes of your time to participate in the interview and complete the short questionnaire. You will be reimbursed for your time and participation with a \$50 supermarket voucher.

What opportunity do I have to consider this invitation?

You will have four weeks to consider this invitation.

Will I receive feedback on the results of this research?

If you would like to receive a summary of the results from this research, please let us know by indicating so on the relevant section of the Consent Form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Primary Researcher, Sarah Stewart, sarah.stewart@aut.ac.nz, (09) 921 9666 ext 5451, 022 409 9343.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, ethics@aut.ac.nz, (09) 921 9999 ext 6038.

Whom do I contact for further information about this research?

If you would like to participate in this study or have any questions about the study, please contact Sarah using the contact details below:

Email: sarah.stewart@aut.ac.nz; **Phone:** (09) 921 9666 ext. 5451; **Mobile:** 022 409 9343

Consent Form

Project title: *The experiences and perceptions of gout flares and physical activity in people with gout*

Researchers: *Dr Sarah Stewart, Libby Anderson (Ngāti Maniopoto-Waikato), Prof Tania Ka'ai (Ngāti Porou, Ngāi Tahu), Dr Irene Zeng, Prof Nicola Dalbeth, A/Prof David Rice, Prof Nicola Kayes, and Dr Julie Collis.*

- I have read and understood the information provided about this research project in the Information Sheet dated 21st September 2023.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.

I wish to review the audio recording transcripts from my interview (please tick one): Yes No

I wish to receive a summary of the research findings (please tick one): Yes No

I wish for my name and contact details to be recorded so that I can be invited to participate in future research studies about gout (please tick one): Yes No

Participant's signature: _____

Participant's name: _____

Participant's Contact Details (if appropriate):

Date: _____

Approved by the Auckland University of Technology Ethics Committee on 26.10.23 AUTEK Reference number 23/305

Note: The Participant should retain a copy of this form.