

ONLINE PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Australian Longitudinal Study on Back and Neck Pain

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2023-027

PRINCIPAL INVESTIGATOR: Dr Rutger de Zoete

You are invited to participate in the research project described below.

What is the project about?

Neck and back pain are common problems in the general population and have large effects on personal lives and health care expenditures. Current treatment options for people with back and neck pain are often ineffective because the underlying mechanisms of the treatments are poorly understood. The purpose of this research is to explore the individual, societal, and economic impact of back and neck pain. To investigate this, you are being asked to participate in an online survey.

Who is undertaking the project?

This project is a collaboration between researchers from The University of Adelaide and The University of South Australia. The Chief Investigator is Dr Rutger de Zoete at the School of Allied Health Science and Practice, The University of Adelaide.

Who can participate in the research?

Inclusion criteria

- Person living in Australia
- At least 18 years old
- Neck pain or back pain as primary complaint

Exclusion criteria

- Other types of chronic pain as primary complaint

What am I being invited to do, and how much time will my involvement in the project take?

If you agree to participate, you will be asked to do the following:

- Complete online questionnaires about back and/or neck pain. This will take between 30 and 60 minutes
- After completing the questionnaires for the first time, you will be asked to complete the same questionnaires annually. You will receive a reminder for this via email.

What are the potential risks and benefits of the research project?

Benefits

- It is widely acknowledged that back and neck pain are a major health burden. The information collected in this research project is of great interest to researchers and clinicians working with individuals with back and neck pain. If you wish to receive a plain language summary of the study results, you can indicate this on the Participant Consent Form.
- Everyone who completes the annual survey by its due date will go into the Prize Draw with a chance to win a Gift Card. Prizes are available as follows:

1 st Prize	1 x \$500 Australia Post Gift Card by Mastercard®
2 nd Prize	2 x \$250 Australia Post Gift Card by Mastercard®
3 rd Prize	20 x \$50 Australia Post Gift Card by Mastercard®

Winners will be notified by telephone or email within seven days of the draw. Terms and Conditions apply, please visit www.painstudy.org.au to view all Terms and Conditions.

Risks and burden

- The anticipated risk and burden of this research project are minimal and very low. Participants are asked to complete the annual survey at a time and place convenient to them, prior to the due date. They can save the draft survey as they progress so that they can complete and finish the survey at a later time.

Can I withdraw from the project?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate, you may withdraw from the project at any time without giving a reason. If you decide to withdraw from the study, you can inform the researchers of this decision after which a 'Withdrawal of Consent Form' can be signed. With this form, you can indicate if your data should be destroyed upon withdrawal, or whether it can be used for future analyses. This study is free of cost and therefore there will be no expenses incurred to participate or withdraw from this study.

What will happen to my information?

The findings of this research will be used by the researchers for research articles submitted for publication in peer-reviewed scientific journals, and conference presentations. Individual participants will not be identified in any reports arising from the project. Non-identifiable data may also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law. In case the researchers wish to use your non-identifiable data beyond the purposes of this research project, they will contact you to obtain appropriate consent. If you agree to be contacted, you can indicate this on the consent form. In case you do not consent, you will not be contacted. Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law. Your contact details (phone number, email address) will be collected in order to contact you throughout the study period.

How will my privacy be protected?

During the first measurement session and before any data is collected, you will be assigned a numerical code. A list of codes and corresponding participant names will be kept separate (and securely stored) from coded data. Collected data will only be stored using the numerical code. Data will be stored on a password protected computer in the School of Allied Health Science and Practice at The University of Adelaide and are only accessible by above mentioned researchers. Any information collected by the researchers which might identify you will be stored securely and will only be accessible by the researchers unless you consent otherwise, except as required by law. Data will be retained for at least 5 years at the School of Allied Health Science and Practice at The University of Adelaide and will then be securely destroyed; electronic data will be erased and hard copies will be shredded.

Who do I contact if I have questions about the project?

If you would like further information please contact Chief Investigator Dr Rutger de Zoete via email: rutger.dezoete@adelaide.edu.au.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2023-027). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

Please read this Participant Information Sheet and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact Chief Investigator Rutger de Zoete using the details below. If you would like to participate, please contact Chief Investigator Rutger de Zoete via the details supplied below. You will be asked screening questions and, if you fit the inclusion criteria, you will be asked to complete a written consent Form. As part of the Participant Consent Form, you will be given the option to agree to the following statement: "I give consent for my contact details to be used for future research purposes, and for the researchers to use the data for secondary reasons unrelated to this research project." If you agree to this, your contact details may be used to contact you for future projects. Further, if the researchers conduct new studies in which your data could be beneficial, they may choose to include your data for secondary analysis purposes.

Yours sincerely,
Dr Rutger de Zoete