

**45 and Up Study Participant Information Sheet**

# Ageing, Society and Wellbeing

September 2025

This Flinders University research project is in addition to the main 45 and Up Study. Participation is voluntary. Participation in this project does not change your involvement in the main 45 and Up Study. Information collected by this research project will become part of the 45 and Up Study in the future.

**What is this research project about?**

This project will investigate the extent to which people report being treated differently due to their age, how they view the process of ageing, and how this may relate to aspects of health and wellbeing.

Taking part in this research project is completely voluntary.

Please read this information carefully and ask questions about anything that you don't understand or want to know more about.

**Who is running the research project?**

The research project Ageing, Society and Wellbeing is being carried out by researchers at Flinders University, including:

- Professor Tim Windsor
- Dr Stephanie Wong
- Dr Bethany Wilton-Harding
- Dr Larissa Roberts



This research project is funded by The Australian Research Council.

**Who can take part in the research project?**

You are invited to take part in this research project because you are a participant in the Sax Institute's 45 and Up Study and currently live in Australia.

**How do I join this research project?**

If you agree to participate in the research project, we ask you to read, complete and submit the consent form.

If you are not interested in participating, you do not need to do anything further, but if you wish to you can inform the 45 and Up team by emailing [45andUp@saxinstitute.org.au](mailto:45andUp@saxinstitute.org.au) or calling the Infoline 1300 45 1145. Your details will not be shared unless you give consent to join this research project.

**What will the research project involve for me?**

This study involves two parts that can be completed in either one or two sittings:

You will first be asked to respond to an online questionnaire that we expect to take about 25-35 minutes to complete. You may stop the survey part way through and come back to complete it using the same device within two weeks. The questionnaire includes some general questions about you (e.g., your age, gender, education, and ethnicity), as well as questions about how you view ageing in general, how you experience your own ageing, your health, mental health, and personality. Please note the survey may take a bit longer if using a smartphone rather than a computer.

Following the questionnaire, you will be asked to undertake a one-off series of short online cognitive tasks. This involves three tasks and will take approximately 10-15 minutes in total. If you like, you can choose to complete these tasks at a later time. To complete these tasks, you will need to be

using a desktop or laptop computer. If you do not have access to a computer, you may choose not to continue with the cognitive tasks – we can still use your survey responses.

If you take part in this research project, the researchers may also contact you later in the year with an invitation to take part in an additional study. This additional study is also voluntary and there is no expectation for you to participate. The second study involves filling out short daily surveys for approximately two weeks. Please note that places in this second study are limited and not everyone will receive an invitation. **If you are not interested in the additional study, we would still greatly value your participation in this survey.**

By signing the consent form, you consent to the research project investigators collecting and using personal/health information about you. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

Any information obtained that can identify you (such as your name and email address) will be stored on a secure drive at Flinders University and all files will be password protected. Any identifiable information will not be shared with anyone outside of the research project team without your permission and we will make sure to keep this information separate to your survey responses.

As part of this research project, the information collected will be linked to health information that you have already provided to the 45 and Up Study and to records that you have previously allowed the 45 and Up Study to access.

### Can I withdraw once I've started?

Being in this research project is completely voluntary and you do not have to take part.

If you wish to withdraw, you can do so at any time without having to give a reason. Your decision will not affect your current or future relationship with the researchers or anyone else at Flinders University, your involvement in the main 45 and Up Study, or the Sax Institute. You can withdraw from the research project and remain in the 45 and Up Study.

If you decide to withdraw consent for participation in this research project or if you decide to take part in the project and then change your mind and want to withdraw, please contact the 45 and Up Study team on the Infoline 1300 45 11 45 or by email [45andUp@saxinstitute.org.au](mailto:45andUp@saxinstitute.org.au). The Study team will

advise the research project team about the withdrawal.

If you choose to withdraw, we will not collect any more information from you. If participants choose to withdraw, personal information will be deleted and removed. Information already collected will be kept in our records and may be included in the project results with any identifying details removed.

### Are there any risks or costs?

Some of the questions asked deal with potentially sensitive topics. For example, we will ask if you have experienced being treated differently than others (e.g., *you are treated with less courtesy than other people are*) or if you have experienced losses as a result of getting older (e.g., *with my increasing age, I have less energy*), or questions about your mental health and wellbeing (e.g., *I lead a purposeful and meaningful life*). Please consider whether answering these types of questions about yourself is likely to make you feel distress or discomfort and use that assessment to inform your decision about whether to participate. Of course, if you begin the research project and decide that you would prefer not to answer the questions, you are free to withdraw your participation at any time. You can also choose to not answer certain questions.

If needed, you can also seek assistance and information from the following organisations:

- Lifeline – 13 11 14 (24 hours, 7 days)
- Beyond Blue – 1300 22 46 36 (24 hours, 7 days) or chat online [www.beyondblue.org.au/about/contact-us](http://www.beyondblue.org.au/about/contact-us)

### Are there any benefits?

There will be no immediate personal benefit to you from your participation in the research project. However, this study will directly address the World Health Organization's call for population-based surveys to better estimate how often people are treated differently based on their age, who is more likely to perceive being treated differently, and how people view their own ageing. Understanding more about ageing and age-based treatment will contribute to national wellbeing through a fairer society that recognises and values the contributions of people of all ages.

## **What will happen to information that is collected?**

By agreeing to be part of this research project, you agree to the Sax Institute providing the investigators with:

- Information relevant to this research project that you previously provided to the 45 and Up Study including information from questionnaires
- Data and/or information that you provide as part of this research project
- Information relevant to this research project that is collected via data linkage as part of the 45 and Up Study

Survey answers and all the relevant information that you have consented to the Sax Institute giving to the Ageing, Society and Wellbeing researchers will be collected and stored on a secure drive at Flinders University.

After a period of 5 years, any information related to this project within the research project site will be permanently deleted from the computer system and any hard copies will be destroyed. Consistent with open science practices, de-identified data will also be made available via Flinders Repository of Open Access DataSets.

The information will also become part of the 45 and Up Study resource. It will be stored by the Sax Institute for the life of the 45 and Up Study plus 7 years and combined with other information from the 45 and Up Study. All future research projects using this information will require approval from a relevant human ethics committee and the Sax Institute.

By providing your consent, you are agreeing to us collecting information about you for the purposes of this research project and any future approved 45 and Up Study research. Any information you provide to us will be stored securely and we will only disclose it with your permission unless we are required by law to release information. There will be no identifiable information published from the research project or any other research.

It is anticipated that the results of any research will be published and presented in a variety of forums. All results will be published and presented in summarised formats and will be provided in such a way that you will not be individually identifiable in these publications or presentations.

The conduct of the 45 and Up Study is overseen by the University of NSW Human Research Ethics and Committee and the conduct of the Ageing, Society and Wellbeing research project is overseen by the Flinders University Human Research Ethics Committee

## **Will I be told the results of the research project?**

All participants can indicate if they are interested in receiving feedback about the overall results of this research project. Participants who respond that they wish to be provided with results will be sent an email with a summary of the results once the results are in a published form. No individual results can be provided. As it is not currently known how any future 45 and Up Study approved research project may use the information collected, it will not be possible to provide feedback for any other projects.

## **What if I would like further information?**

For any questions or comments about this research project, or if you wish to withdraw consent for participation, please contact the 45 and Up Study at the Sax Institute by email [45andUp@saxinstitute.org.au](mailto:45andUp@saxinstitute.org.au) or call the Infoline 1300 45 11 45.

## **What if I have a complaint or any concerns?**

You can always contact the 45 and Up Study with any questions or issues.

This research project has been approved by Flinders University's Human Research Ethics Committee (Project ID 8155). If you have any complaints or reservations about the ethical conduct of this study, you may contact Flinders University's Research Ethics and Compliance Office via telephone on 08 8201 2543 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)

# About the 45 and Up Study

The 45 and Up Study is the largest general population program of health-related research ever conducted in Australia. More than 267,000 people aged 45 and over are participating in the Study, and they are being followed over time through routine follow-up questionnaires and linkage to health and other records.

The 45 and Up Study has been approved by the University of New South Wales Research Ethics Committee. Study participants have also given permission to be invited to participate in further research projects. Each of these research projects has been through a stringent review process prior to approval. Participation in these research projects is optional.

## Study governance

The 45 and Up Study is owned and managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the Heart Foundation; NSW Ministry of Health; NSW Department of Communities and Justice; and Australian Red Cross Lifeblood.

## About the Sax Institute

The Sax Institute is an independent, not-for-profit organisation that improves health and wellbeing by driving better use of evidence in policies, programs and services.

The Institute is a registered charity that works with governments, health organisations, research organisations and a network of experts nationwide to analyse policy problems and find the best evidence-based solutions.

## Contact the Sax Institute about the 45 and Up Study

For any questions, comments, or complaints about the 45 and Up Study or this research project, to withdraw consent for participation or for further communication, please contact us:

**Telephone:** 1300 45 11 45 (toll-free Study Infoline)

**Email:** [45andUp@saxinstitute.org.au](mailto:45andUp@saxinstitute.org.au)

### In writing to:

Dr Martin McNamara, Chief Investigator,  
45 and Up Study, GPO Box 5289, Sydney NSW  
2001

## Confidentiality

The 45 and Up Study, and any research projects associated with it, are bound by Commonwealth and State privacy legislation and guidelines: the Privacy Act 1988 (Cth), Health Records and Information Privacy Act 2002 (NSW); and the NSW Health Privacy Manual for Health Information. The 45 and Up Study has strict procedures and systems in place to safeguard participant confidentiality. The Study is also bound by strict scientific ethical accountability to the University of New South Wales:

### Ethics Secretariat,

University of New South Wales,  
Sydney NSW 2052

**Telephone:** (02) 9385 6222

**Email:** [humanethics@unsw.edu.au](mailto:humanethics@unsw.edu.au)

**Thank you.** We could not conduct the 45 and Up Study without the generosity of our participants. We are immensely grateful to all of you. **This information sheet is for you to keep.**