

**45 and Up Study Participant Information Sheet**

# AgeWell – Health Insights of Ageing Australians

May 2025

This 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 future.

**What is this research project about?**

Smart sensors either worn on the body or placed inside homes can provide valuable information about the health of an individual and their daily routines, that could facilitate management of their health and wellbeing.

This research project aims to explore how data collected from sensors can reveal relationships between behaviour, demographics and health outcomes, such as social isolation, depression and anxiety. This insight will enable the delivery of early, effective, and personalised healthcare.

Participation in this research project is entirely voluntary. Please read this information carefully and ask questions about anything that you do not understand or would like to know more about.

**Who is running the research project?**

The AgeWell project is being conducted by researchers at the Commonwealth Scientific and Industrial Research Organisation (CSIRO), and the University of New South Wales (UNSW), including:

- Principal investigator Dr Marlien Varnfield (CSIRO)
- Dr David Silvera (CSIRO)
- Dr Margo Barr (UNSW)
- Liesel Higgins (CSIRO)
- Dr Mahnoosh Kholghi (CSIRO)
- Dr Deepa Prabhu (CSIRO).

The research project is being funded by CSIRO and UNSW.

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

You are invited to take part because you are a participant in the Sax Institute's 45 and Up Study.

Participants in this research project must meet the following eligibility criteria:

- Be aged 45 years or older
- Live independently in the community
- Have access to a smartphone, tablet, or computer
- Be able to speak and write in English
- Be contactable via email
- Live in the Greater Sydney Area.

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

If you agree to participate in this project, we ask you to read, complete and submit the consent form. There is a personalised weblink in the invitation email that you received.

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 11 45. Your details will not be shared unless you give consent to join this research project.

**What will the research project involve?**

Your participation will involve:

- Authorising the installation of ambient sensors in your home, for the 3-month study period
- Wearing a Garmin fitness tracker on your wrist for at least one week in each of the 3 months of the study
- Completing a series of online surveys
- The opportunity to share your experience in a post-study interview.

***Wearable and ambient sensors:***

If you consent to participate in this project, the CSIRO/UNSW research team will arrange a time

with you over the phone or email for an accredited CSIRO or UNSW individual to install ambient sensors and a Vera hub (an electronic management system that routes all the data from the sensors to databases) in your home and provide you with a Garmin fitness tracker to be worn on the wrist.

These devices will collect data on:

- The temperature, humidity, and light levels in your home
- Movements throughout the house
- The use of power in some locations of your home
- Your heart rate and breathing rate
- Your levels of physical activity.

All data collected from sensors will be de-identified. No videos, audio, or images will be collected.

You will not need to interact with the Vera hub or the smart home sensors in your home at all. Data that is collected by the smart home sensors via the Vera hub will be linked to the research team's Vera account. It will not include any participant's personal information. The data from the smart home sensors will be automatically uploaded to a secure data platform operated by Vera using your existing internet connection. This may be located overseas.

The research team will then access and store this data on a database on CSIRO's existing computer systems. If you do not have an internet connection or have concerns about its use, our research team can organise a wireless internet connection for the duration of this study. More information about how the research team will use and store your home sensor data is provided below.

For the Garmin fitness tracker, the research team will create a profile for you using a made up name and the research team's contact details. The profile data from the wearable device will be stored on servers provided by Garmin which may be located overseas. If you want to, you will be able to access the data from the Garmin fitness tracker using an app installed on your own smartphone. The data usage will be minimal and should not significantly impact your internet/data plan or involve additional costs.

The research team will access the profile data that is linked to the Garmin account for your wearable device and store a copy of this data on CSIRO's existing computer systems. More information about how the research team will use and store your

fitness tracker data is provided below. If you do not have a smartphone or internet connection/plan or have concerns about its use, our research team can organise a tablet or wireless internet connection for the duration of this study.

You will not need to interact with any of the devices, but will need to charge the Garmin fitness tracker (every 5-8 days) and we ask that you wear it for at least one week of each month that you participate in the project. When required, you will be sent a reminder email or text message on your phone to wear the wearable device.

**For more information about the sensors and data they collect**, please refer to this link: [Additional information about home and wearable sensors](#)

Whilst the research team has taken steps to ensure your data is de-identified when it is stored on third party software providers' servers, there is a small risk that you may be re-identified.

If you have any concerns about your personal information being stored on servers used by Vera and/or Garmin, which may be located overseas, you should not participate in this project.

#### *Surveys:*

We will ask you to complete several online surveys via a secure online platform accessible on your phone, tablet or computer to gather information on your mental health and wellbeing, as well as your experiences using the sensor devices. There will be long surveys of approximately 30-45 minutes each at the start, middle and end of the study period (3 in total); and a 3-5 minute short survey every two weeks (4 in total).

Links to the surveys will be sent via email or SMS. You can contact the principal investigator to request a paper-based survey if this is preferred.

Your responses to the surveys will be stored without any identifying information on CSIRO's existing computer systems.

#### *Interview:*

You may be randomly selected to participate in an optional face-to-face or online interview with a member of the research team to discuss your experience of the project and provide feedback on the sensor technology. You may decline the offer to participate in the interview without this affecting your participation in other parts of the project.

These interviews will take approximately 15 minutes. With your consent, the interview will be audio or video recorded using Microsoft Teams.

At the end of the 3-month study period, the UNSW/CSIRO project team will arrange a time with you to collect the sensors and fitness tracker.

### Emergency services monitoring

**This project does NOT offer any emergency services or medical support.** As the data collected in this research project will not be monitored in real time, in case of emergencies during this project follow your standard emergency measures.

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

Participation is voluntary. 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 at the CSIRO, UNSW, the Sax Institute, or your involvement in the main 45 and Up Study. 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 your withdrawal.

If you choose to withdraw, we will not collect any more information from you, your personal information will be deleted and removed. Information already collected will be kept in our records and may be included in the project results in a de-identified manner, where any identifying details will be removed.

If you have already been provided with the sensors, the UNSW/CSIRO project team will contact you to arrange removal and collection of these devices.

### Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any costs associated with taking part in this research project.

Taking part in this project is considered to be of low risk, however, the research team acknowledges that some questions in the surveys/interviews may lead to emotional discomfort.

If needed, you can 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. However, you will be contributing to improving future models of care for older Australians which may have long-term benefits for yourself and others.

To thank you for your time, you will receive a \$50 Visa gift card at the completion of the 3-month study period.

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

By signing the consent form, you agree to the research project investigators collecting and using personal/health information about you. Your information will only be used for the purpose of this project and any approved 45 and Up Study research in the future, and it will only be disclosed with your permission, except as required by law.

You also 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.

Any information obtained that can identify you (such as your name, address, phone number, and email address) will be stored by UNSW in a secure Microsoft Teams folder and kept confidential on secure password-protected computers.

Identifiable information will not be shared with anyone outside of the UNSW/CSIRO research team without your permission. This information will be kept separate from your survey and sensor data.

Your survey data will be entered into a secure CSIRO database in a de-identified form, linked by your email address and a participant ID. Your de-identified sensor data will be stored in an Amazon Web Servers (AWS) database in Australia. All data

will be downloaded into Microsoft Teams (part of CSIRO's secure computer systems) for analysis, and linked using a unique study number to keep your identity anonymous during analysis.

All interviews will be recorded using Microsoft Teams and transcribed using NVivo software, which is also part of CSIRO's secure computer systems. As above, this information will be linked to your identifying details by a unique study number.

After 15 years, any information related to this project held by the research team will be permanently deleted from the computer system and any hard copies will be destroyed.

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.

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

The conduct of the 45 and Up Study is overseen by the University of NSW Human Research Ethics Committee (HREC) and the conduct of the AgeWell Project is overseen by the CSIRO HREC.

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

Should you wish to receive a copy of the results of this research you may contact the principal investigator via email ([marlien.varnfield@csiro.au](mailto:marlien.varnfield@csiro.au)). Please note that individual results will not be available as data will be deidentified and aggregated to protect participants anonymity.

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.

### **How will my privacy be protected?**

Your personal information including your name, contact details, sensor data, and your answers to the surveys and interview is being collected for the purpose of this project, and is protected under the Privacy Act 1988 (Cth). UNSW and CSIRO will handle your personal information in accordance with this Act, the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research 2023, or as otherwise required by law.

Your personal details including your name, address, email address, or phone number will never be made known to anyone other than members of the research team. In the event that this information needs to be disclosed to anyone else or published, it will be done only with your explicit consent.

By participating in this project, you also consent to the transfer of your de-identified information collected by the fitness tracker to Garmin servers that might be located outside of Australia, and you acknowledge that this information may not be subject to the requirements of the Privacy Act. Personal information is securely stored for at least 15 years, after which it is destroyed unless required by law.

We will make all attempts to ensure you cannot be re-identified from the information contained within the publications. However, it is possible that you may be able to be re-identified within due to a combination of demographics and geographic location.

Specifically, third-party involvement in this study may entail:

- Storage of de-identified data on servers provided by third party software providers such as Garmin and Vera
- Publication of study results and data with third-parties in research publications and press releases while ensuring personal information remains de-identified and in aggregate form where possible.

If you have any concerns about being re-identified, you should not participate in this study.

For further details on how your personal information is handled, including access and correction procedures and complaint mechanisms, refer to the CSIRO Privacy Policy available at <https://www.csiro.au/en/About/Access-to-information/Privacy>, or contact [privacy@csiro.au](mailto:privacy@csiro.au)

### **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?**

The ethical aspects of this research project have been approved by CSIRO Human Research Ethics Committee (CSIRO HREC) according to the National Statement on Ethical Conduct in Human Research (2023).

You can always contact the 45 and Up Study with any questions or issues. If you are concerned about the way this project is being conducted or you wish to make a complaint to someone independent from the project, please contact either the CSIRO or UNSW HRECs:

CSIRO: [chmhrec@csiro.au](mailto:chmhrec@csiro.au)

UNSW: [humanethics@unsw.edu.au](mailto:humanethics@unsw.edu.au)  
or (02) 9385 6222



# 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 and the NSW Ministry of Health.

## 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 UNSW HREC:

### 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.