

45 and Up Study

The 45 and Up Study is the largest population-based program of health-related research ever conducted in Australia. More than 267,000 people aged 45 and over are part of the Study and 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 also gave permission to be invited to participate in further research projects. All of these research projects have 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 our major partner Cancer Council NSW and partners The National Heart Foundation (NSW Division); NSW Ministry of Health; NSW Government Family & Community Services – Ageing, Carers and the Disability Council NSW; and the Australian Red Cross Blood Service.



Sax Institute

The Sax Institute is an independent, not-for-profit organisation whose mission is to improve health, health services and programs by increasing the use of research in policy making. We want to achieve wiser decisions for a healthier Australia.

The Sax Institute's objectives are to: generate new research for use in policy; improve policy makers' access to existing research; and develop and test innovative new ways to increase the use of research evidence in policy making. See www.saxinstitute.org.au

Confidentiality

The 45 and Up Study, and any research projects from it, is bound by Commonwealth and State privacy legislation and guidelines: 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 to safeguard 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

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 by:

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

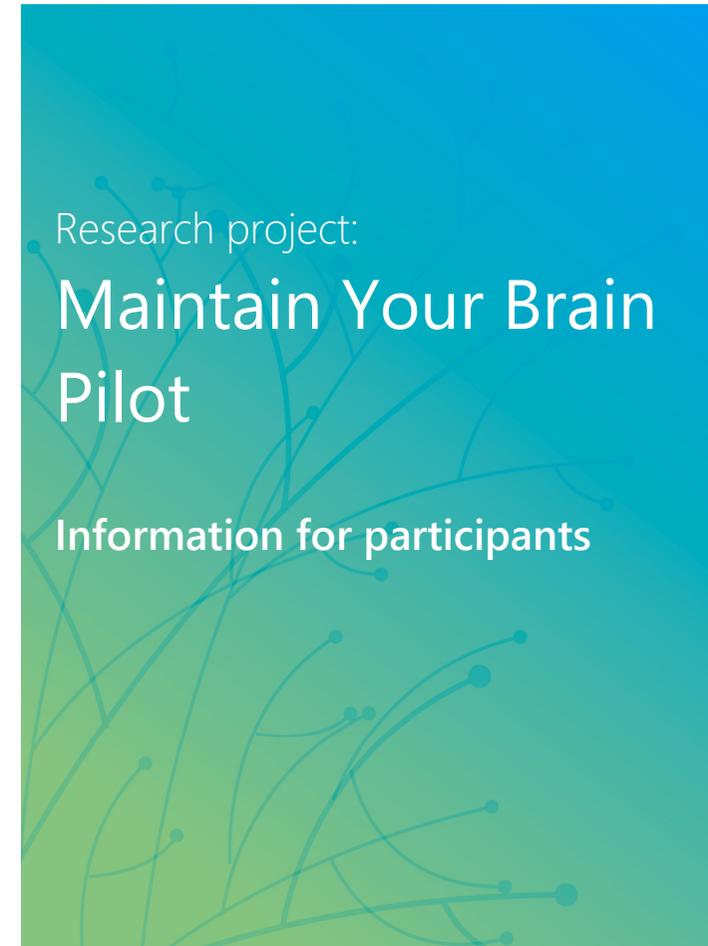
Email: 45andUp@saxinstitute.org.au

In writing, addressing your correspondence to:

Professor Emily Banks, Scientific Director
The 45 and Up Study
GPO Box 5289, Sydney NSW 2001

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.



Maintain Your Brain (MYB)

This research project is in addition to the main 45 and Up Study.

Participation is voluntary. Participation in this research 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.

Purpose of this research

The research project is looking at reducing dementia risk through health modules delivered via the internet. The program will deliver online modules designed to improve physical activity, nutrition, cognitive activity and peace of mind.

Eligibility for participation

You are invited to participate in this research project because researchers are looking for participants who:

- Are enrolled in the 45 and Up Study
- Are aged 55-75 years in 2016
- Have home access to an internet enabled computer or tablet device
- Can speak and write in English

What participation involves

If you choose to take part in the research project you will be asked to do the following things:

- Complete a screening questionnaire about dementia risk factors (approximately 25-30 mins)
- Agree to be randomised to either an 'information' or 'coaching' group

- The coaching group may be asked to complete an online module (3 months) that aims to improve either physical activity, nutrition, cognitive activity or peace of mind. The information group will be asked to view information about relevant dementia risk factors.

Information and document storage

All of the information is saved as data files on a password protected computer. The data files are stored securely by the MYB research team. After the research project is completed the information will be provided to the Sax Institute and stored at the University of New South Wales for 15 years and then destroyed. Research project information provided to the Sax Institute to be used alongside your existing 45 and Up Study data will be kept on a password protected computer for the duration of the 45 and Up Study plus a period of seven years.

Risks for participants

There are possible risks to participating in this research project. You may feel that some of the questionnaire items are upsetting. If so you can contact the study team and referral options will be provided. One module involves changes to physical activity levels. Although participants will be screened and monitored to reduce risks as a result of this, you may experience difficulties.

Benefits of the research project / why is this project important?

There will be no immediate personal benefit to you from your participation in this research project. The research project will however improve the understanding of the use of internet modules to improve dementia risks and that may help reduce the rate of dementia in the future.

Costs and payments

Participation in this research project will not cost you anything and you will not receive any payment for your involvement in the research project.

Information the researchers will receive from the Sax Institute

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

- Information relevant to this research project that you have previously provided to the 45 and Up Study, or that you have already allowed the 45 and Up Study to combine from health and other records

Research project management

This research project is being conducted by the University of New South Wales, The University of Sydney, Monash University, University of Western Sydney, The University of Melbourne and the Australian National University. The research project investigators are:

- Professor Henry Brodaty
- A/Prof Michael Valenzuela
- Professor Perminder Sachdev
- Professor John McNeil
- Professor Anthony Maeder
- Professor Nicola Lautenschlager
- Professor Louisa Jorm
- Professor Maria Fiatarone Singh
- Professor Kaarin Anstey
- Professor Gavin Andrews

Ethics approval and contact information

This research project has been approved by the UNSW HREC and NSW Population and Health Services Research Ethics Committee.

Any person with concerns or complaints about the conduct of this research project should contact the Ethics Coordinator of the UNSW Ethics Committee, who is the person nominated to receive complaints from research participants. You can contact them by email at humanethics@unsw.edu.au. Please quote reference number HC16252.