

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 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 and wellbeing by driving the use of research in policies, programs and services. We want to achieve wiser decisions for a healthier Australia.

The Sax Institute's objectives are to: build and maintain research assets that enable high-quality research and produce new knowledge for decision making; drive research that contributes to policy, program and service delivery decisions; and give health decision makers ready access to relevant research findings and research expertise. 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, including withdrawal of your blood samples 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.

This information sheet is for you to keep.

Research project:

Pilot study for the collection of blood samples through public pathology services

Information for participants

Pilot study for the collection of blood samples through public pathology services

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

This project will support new research to understand the link between genes, biology and the health of people in the 45 and Up Study. It will also give us information about the easiest and most convenient ways to collect blood samples from participants.

Eligibility for participation

You have been invited to participate in this research project because our records show that you live close to a NSW Health Pathology Collection Centre.

What participation involves

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

- Complete a short questionnaire about your current health
- Attend a pathology service collection centre to give a small sample of blood (about two tablespoons/30mls).

Use of my information and blood sample

Your blood sample will not be analysed immediately after collection. Instead, over the next few decades your sample will be stored securely and used for future health research. All research will be approved by a Human Research Ethics Committee, an independent committee

that has ethical oversight of research. Researchers will not be provided identifying information, like your name and address.

Information and document storage

All of the forms that you complete as part of this project are scanned and the information is saved as data files on a password-protected computer server. The forms are stored securely by the Sax Institute and by NSW Health Pathology. After the research project is completed the documents will be shredded and data will be kept on a password-protected computer server for the duration of the 45 and Up Study plus a period of 7 years.

Confidentiality and storage of tissue data

The blood samples will be stored securely at the NSW Statewide Biobank, Level 1, Marie Bashir Centre, 67-73 Missenden Road, Camperdown, NSW. Blood samples will be stored for an indefinite period of time.

Risks for participants

The project is of low risk to participants; however you may feel that some of the questionnaire items are upsetting and there may be some discomfort from having blood collected. If required please contact our Infoline 1300 45 11 45, or by email 45andUp@saxinstitute.org.au and referral options will be provided.

During future studies, researchers might find out important information about your health or your blood relatives' health. This might be about your health right now, or about your risk of getting sick in the future.

If something important is found, you will be contacted to see if you would like to receive these results. If you decide you want to find out the results, they will be provided to you by a genetic counsellor or similar health professional.

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. This project will provide insights into the most efficient way for large

scale blood collections to be included in cohort studies. However, collecting updated health information as well as blood samples will allow the 45 and Up Study to facilitate more in depth research into factors affecting healthy ageing that may lead to the potential for individualised treatment for future patients.

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
- Questionnaire data and/or information that you provide as part of this research project.

Research project management

This research project is being conducted by the Sax Institute and NSW Health Pathology. The research project investigators are:

- Professor Roger Wilson
- Dr Martin McNamara

Questionnaire data collection will be managed by the Sax Institute and blood collections will be collected and managed by NSW Health Pathology.

Ethics approval and contact information

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District.

Any person with concerns or complaints about the conduct of this research project should contact the Executive Officer on (02) 9515 6788 and quote protocol number X17-0354.