

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 of Australia (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.

This information sheet is for you to keep.



Research project:

A study of self-care strategies for coping and living with chronic illness

Information for participants



A study of self-care strategies for coping and living with chronic illness

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 people's treatment and management of chronic illness. We are particularly interested in the things that you do to improve your health that are outside of your conventional medical care (self-care). Self-care is an important component of chronic disease management and we aim to better understand how people cope and live with chronic illness.

Eligibility for participation

You have been invited to participate in this research project because our records show that you indicated on a prior 45 and Up Study questionnaire that you have been diagnosed with high blood pressure or as having had a stroke in the past. If you have experienced both of these chronic conditions, you have been selected to provide information on one of them as specified in the invitation letter and questionnaire.

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 how you manage your chronic health condition. You will be asked questions about your use of health care

services i.e. your visits to conventional health care practitioners along with any self-care practices that you use to manage your chronic illness. We will also ask you questions about your general health and wellbeing.

- We will select some participants for an additional in-depth interview. If you are selected, you will be asked questions about your experiences of using self-care to manage a chronic illness including your beliefs, attitudes, communication and information seeking in relation to self-care.

Information and document storage

All of the forms are scanned and the information is saved as data files on a password-protected computer. The documents are then stored securely by the Sax Institute. After the research project is completed the documents will be shredded and data will be kept on a password-protected computer for the duration of the 45 and Up Study plus a period of 7 years. Information obtained from the in-depth interviews will be stored securely on a password-protected computer for the lifetime of the study plus 7 years.

Risks for participants

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

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. Chronic illness is the single greatest burden on the Australian health system. Yet, the needs of those with chronic illness often remain unmet. As a result many people use complementary self-care to help manage their condition. This study will provide insights into the rise of self-care and its role in helping people live with chronic illness.

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
- Contact information (name and telephone number) for participants who are selected for a more in-depth interview

Research project management

This research project is being conducted by the University of Technology Sydney. The research project investigators are:

- Professor Jon Adams
- Professor David Sibbritt
- Professor Alex Broom
- Dr Jane Frawley

Questionnaire data collection will be managed by the Sax Institute and interview data will be collected and managed by the research team.

Ethics approval and contact information

This research project has been approved by the University of Technology Sydney ethics committee.

Any person with concerns or complaints about the conduct of this research project should contact the Ethics Coordinator of this ethics committee, who is the person nominated to receive complaints from research participants. You can contact them on 02 9514 9772, or by email at research.ethics@uts.edu.au. Please quote reference number ETH17-1180.