

45 and Up Study

The 45 and Up Study is the largest study of its kind ever conducted within Australia and in the Southern Hemisphere. The 45 and Up Study is a longitudinal cohort study: the same sample of people is followed over time and asked for updates on health and lifestyle at key points. This study has been approved by the University of New South Wales Research Ethics Committee.

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.



Confidentiality

The 45 and Up Study, and any research projects from it, is bound by these 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. The 45 and Up Study also 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.

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 Institute collaborates widely to develop research programs that strengthen health policy. Our membership is a coalition of public health and health services research groups and their universities. Our 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.

www.saxinstitute.org.au

Contact the Sax Institute about the 45 and Up Study

If you have any questions, comments or complaints about this research project or the 45 and Up Study, or you wish to withdraw consent for this research project 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.

For any complaints you may also contact:

Ethics Secretariat, University of New South Wales,
Sydney NSW 2052. Phone: (02) 9385 6222.

Email: humanethics@unsw.edu.au



saxinstitute

Research project:

Collecting Cancer Statistics in NSW Study

Information for Participants



cancer
institute
NSW

Collecting Cancer Statistics in NSW Study

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

Participation is voluntary and 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 and used for future research projects.

What is the purpose of this research project?

The research project is looking at how to best monitor and improve outcomes of cancer services in NSW. A key issue for monitoring is whether or not cancers have come back or progressed.

Why have I been invited to participate in this research project?

You were invited to participate in this research project because your previous 45 and Up questionnaire information and/or your NSW Cancer Registry record indicated that you may have had a cancer. If this information is incorrect, please let us know on our Infoline 1300 45 11 45, or by email 45andUp@saxinstitute.org.au and we will remove you from the study – we apologise for having troubled you.

What does participation in this research project involve?

If you choose to take part in the study you will be asked to:

- Complete and sign the enclosed consent form providing us with permission to contact your cancer specialist to receive medical information about your cancer history
- Provide us with your cancer specialist's name and contact details and approval to contact them

- Complete a short questionnaire about your health and whether or not your cancer has come back or progressed

What happens to the research project consent form, questionnaire, and information from my specialist?

All of the forms are scanned and the information is saved as data files. The documents are stored securely by the Sax Institute.

Are there risks to me in taking part in this research project?

We don't anticipate any significant risks; 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.

Will I benefit from this research project?

There will be no immediate personal benefit to you from your participation in this research project, but it will provide important statistics on whether or not cancers have come back (recurred) or progressed. This will help us evaluate health service outcomes in NSW.

Will taking part in this research project cost me anything, and will I be paid?

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

What information will the researchers receive about me 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 including information from questionnaires and from health datasets
- Questionnaire data and/or information that you provide as part of this research project
- Information from your doctor about your cancer outcome

Who is conducting this research project?

The research is being commissioned by the Cancer Institute NSW, Sydney.

The research project investigators are:

- Professor David Currow, Cancer Institute NSW
- Professor David Roder, Cancer Institute NSW
- Dr Stephen Morrell, Cancer Institute NSW
- Richard Walton, Cancer Institute NSW

All of the data collection is being organised by the Sax Institute.

What ethics approval does this research project have and how can I contact them?

This research project has been approved by the NSW Population & 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 ethics committee who is the person nominated to receive complaints from research participants. You should contact them on 02 8374 5600 and quote reference number (2014/05/531).