The 45 and Up Study is owned and managed by the Sax Institute, in collaboration with our major partner Cancer Council NSW.

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 37 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

45 and Up Study partners

In addition to our major partner, Cancer Council NSW, there are a further four important partners that make the 45 and Up Study possible. These are: the National Heart Foundation of Australia (NSW Division); NSW Ministry of Health; NSW Government Family & Community Services – Carers, Ageing and Disability Inclusion; and the Australian Red Cross Blood Service.

The 45 and Up Study also acknowledges support provided by other organisations, including beyondblue, UnitingCare Ageing, the BUPA Foundation, the Macquarie Group Foundation, Freehills, The Baxter Charitable Foundation and Alma Hazel Eddy Trust (managed by Perpetual Limited), and the NSW Office of Science and Medical Research.

We could not conduct the 45 and Up Study without the generosity of our participants. We are immensely grateful to all of you.

The 45 and Up Study relies on the willingness of people to share information about their lives and experiences and to have their health followed over time. By signing this form you are agreeing to take part in the 45 and Up Study Follow-up and for that information to be used for health research. Participation is completely voluntary, and you are free to ask questions or withdraw from the Study at any time by calling the Study Infoline on 1300 45 11 45.

More information on the Study can be found at www.saxinstitute.org.au/our-work/45-up-study

Follow-up Questionnaire

Information for Participants

The 45 and Up Study is the largest population-based program of health-related research ever conducted within Australia and in the Southern Hemisphere. Thank you for remaining in the community of more than 265,000 participants – men and women aged 45 and over who, like yourself, are helping us to better understand “living well” in mid to later life.

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. The results will continue to provide valuable information for the whole community on how to best support health throughout life. Priority topics for research include how to maintain wellbeing and independence; the impact of and risk factors for major diseases such as diabetes, cancer, arthritis and heart disease; and how to best plan health services for illness prevention in the healthy, as well as for treatment.

I give my consent on the understanding that:
• my information will only be used for the purposes outlined in the participant information leaflet entitled “Follow-up Questionnaire Information for Participants”, of which I have a copy;
• my information will be kept strictly confidential and will be used for health research only;
• reports and publications from the Study will be based on de-identified information and will not identify any individual taking part;
• my participation in this Study is entirely voluntary and my consent will continue to be valid following death or disablement unless withdrawn by my next of kin or other person responsible. I am free to withdraw from the 45 and Up Study and/or the 45 and Up Study Follow-up at any time by calling the Study Infoline on 1300 45 11 45.
• my decision whether or not to take part in the 45 and Up Study Follow-up or in any additional research will not disadvantage me or affect my future health care in any way.

I have been provided with information about the 45 and Up Study Follow-up, including how it will gather, store, use and disclose information about me, in the participant information leaflet. I have been given an opportunity to ask questions and have been fully informed about the Study.

I agree to take part in the 45 and Up Study Follow-up by:
• permitting the long-term storage and use of the information from my questionnaire for health-related research;
• the 45 and Up Study team combining the information I have given in this questionnaire with other health information that is part of the 45 and Up Study, including other questionnaire information and Medicare, medication, hospital, cancer, death and other health-related records, as outlined in the leaflet “Follow-up Questionnaire Information for Participants”.

FOR YOUR RECORDS ONLY

Here is copy of the information contained in the Study consent form for the Follow-up questionnaire.
Why have I received this questionnaire?
Between 2006 and 2009, you were one of more than 265,000 people aged 45 years and over who joined the 45 and Up Study by completing a questionnaire about your health and lifestyle. At that time, you gave us permission to recontact you to follow your health over time. We are now conducting the first follow-up survey. Over time, it will be sent to every 45 and Up Study participant.

The questionnaire has been developed by leading Australian and international health professionals and researchers. Topic areas include general questions about your lifestyle and everyday choices (e.g., your diet and physical activity). There are also more specific questions about your physical health (e.g., whether you have received treatment for particular health concerns) and your psychological wellbeing (e.g., how you’ve been feeling over the past 4 weeks).

What am I being asked to do?
We are asking you to:
- Please complete the questionnaire. It will take about 30 to 45 minutes of your time.
- Please complete the consent page at the end of the questionnaire. Your consent is VERY important. It gives us permission to use the questionnaire information you provide, and to link it to both the previous details you have provided to the 45 and Up Study and to the health and other records that you allowed the 45 and Up Study to access.
- Please return the questionnaire to us in the supplied reply paid envelope or submit online.

If you do choose to take part, please remember that you are still free to withdraw from the Study at any time by contacting our Infoline on 1300 45 11 45.

How will my information be used?
Your information will be used only for approved research projects investigating factors that affect the health of Australians in mid to later life. Each research project must demonstrate it is in the public interest with the potential to provide important information to improve health.

To help research projects investigate changes in the health of Australians over time, the information you give in this follow-up questionnaire will be combined with your answers from the first questionnaire that you completed between 2006 and 2009.

Your answers may also be linked to information about you and your health from other records that you allowed the 45 and Up Study to access (when you first consented to take part in the Study). These records include health service use (e.g., hospital admissions, and Medicare Australia data such as claims and prescriptions), specific illnesses (e.g., cancer and other notifiable diseases in NSW), and other records (e.g., Births, Deaths and Marriages Register).

Some researchers may request permission to link your answers to other types of Commonwealth and State population records. These projects will require ethics committee approval and we will inform you of approved studies in our participant newsletter, 45&Update, and on our website. For a full list of linked information sources and current research projects, please call 1300 45 11 45 or visit www.saxinstitute.org.au/our-work/45-up-study

What happens if I do not complete this questionnaire?
Unless we hear from you, the 45 and Up Study will continue to follow your health over time and we will also continue to keep you updated about the research program. This will include invitations to participate in projects, including these follow-up questionnaires. To change your participation profile please contact us directly (see “How can I contact the 45 and Up Study?” in this leaflet).

Our commitment to security and confidentiality
The 45 and Up Study 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.

All information will be kept strictly confidential and will be used for health research only.

To further ensure security, confidentiality and anonymity, all information will be analysed and reported with your identifying details removed. No information will be released, without your prior written consent, in a way that would allow an individual or household to be identified except as required by law.

In addition to strict scientific ethical accountability to the University of NSW Human Research Ethics Committee, the Study is also independently monitored by community representatives consulted by The Sax Institute.

How can I contact the 45 and Up Study?
If you have any questions, comments or complaints about the Study, or you wish to withdraw consent 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:
Human Research Ethics Coordinator
+61 2 9385 6222
humanethics@unsw.edu.au