

Follow-up Questionnaire: Information for Participants

Why have I received this questionnaire?

Between 2006 and 2009 our records show that you 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. This questionnaire is a follow-up to the original and other 45 and Up questionnaires.

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).

Who is conducting this research?

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

- Heart Foundation
- NSW Ministry of Health
- NSW Government Family & Community Services – Ageing, Carers and the Disability Council NSW
- Australian Red Cross Blood Service.



What am I being asked to do?

You are being asked to:

- complete the questionnaire. It will take about 30 to 45 minutes of your time.
- return the questionnaire 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.

What happens if I don't 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.

How will my information be used?

Your information will be used only for approved research projects. Each research project must demonstrate it is in the public interest with the potential to provide important information to improve health. The information you give in this follow-up questionnaire will be combined with your answers from previous questionnaires.

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), 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, *Catch Up*, 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

How is the data kept confidential?

The 45 and Up Study 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: Human Research Ethics Coordinator, University of New South Wales, Sydney NSW 2052
Telephone: (02) 9385 6222
Email: humanethics@unsw.edu.au

Contact details for the Study

For any questions, comments or complaints about the 45 and Up Study, to decline or 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:

Dr Martin McNamara, Chief Investigator

The 45 and Up Study

GPO Box 5289, Sydney NSW 2001