



THE 45 AND UP STUDY

Research to improve health and wellbeing

Information for participants

What is the 45 and Up Study?

The 45 and Up Study is the largest follow-up study ever conducted in Australia and in the Southern Hemisphere. More than 250,000 NSW men and women aged 45 and over are needed to participate in this large scale study and to provide information about their health and use of health services. Close to 100,000 people have already joined the Study.

This study is unique in that this large group of people will be followed over time to provide new information that will help answer many important health questions. It will also assist in the future planning for Australia's ageing population, including understanding the impact of major diseases like cancer and heart disease, the quality of life of older people and their use of health services.

Who is conducting the Study?

The 45 and Up Study involves the work of over 120 leading NSW health and medical researchers – the largest collaborative effort ever seen in an Australian health study. The Study is being conducted by the Sax Institute, in collaboration with The Cancer Council NSW, the National Heart Foundation of Australia (NSW Division), NSW Health and *beyondblue: the national depression initiative*, with support from the Macquarie Bank Foundation, Freehills legal services, the Baxter Charitable Foundation and Alma Hazel Eddy Trust (both managed by Perpetual Ltd), and the MBF Foundation.

Auspiced by:



In collaboration with:



NSW HEALTH





Why have I been sent a questionnaire?

Because we need you – you are one of the 250,000 NSW men and women who have been randomly selected to take part in the Study. This represents around 10% of the population in this age group and for reliable research we need as wide a range of people as possible to join it – men and women from 45 to 105, from all walks of life, all social and ethnic backgrounds and all lifestyles and interests.

What do I need to do?

To take part all you need to do is complete the enclosed questionnaire that should take around **30-45 minutes**. Please make sure you also sign the consent form **on the back of the questionnaire** before enclosing it in the reply-paid envelope, so we can follow your health over time. A follow-up questionnaire will be sent to you within 5 years after joining the Study to update information about your health and lifestyle.

At some stage you may also be invited to take part in additional research or to provide saliva or blood samples. It is entirely your choice whether you take part in this study and in any future studies. If you do choose to take part, you are free to withdraw from the Study at anytime, by calling the helpline on 1300 45 11 45.

What sort of information do you need from me?

The questions have been developed by leading NSW health professionals and research organisations and include general questions about you and your family (such as your age, education and employment) and more specific questions about your health and wellbeing, lifestyle, diet, existing medical conditions, disability, use of medication, health insurance and social connections. This questionnaire is for you to fill out yourself; you should not need to contact a health professional to get information to complete it. Please be as accurate as you can, but remember that an approximate answer is still very valuable for the Study. If you don't want to answer a question for any reason, you don't have to.

How do I know my information will be treated confidentially?

This study is bound by Commonwealth and State privacy legislation, including the Health Records and Information Privacy Act and the NSW Health Privacy Manual.

All information collected will be treated **completely confidentially and used for health research only**.

To further ensure security, confidentiality and anonymity, all information will be stored, analysed and reported on with your identifying details removed. No information will be released in a way that would allow an individual or household to be identified, except as is required by law. In addition, the Study has an independent Community and Ethical Oversight Committee and is accountable to the University of NSW Human Research Ethics Committee.

How will information from the Study be used to help me and others?

Information from the 45 and Up Study will give us a better understanding of what determines healthy ageing and how individuals and health services can act to prevent ill-health and improve the quality of life of current and future generations. Collaborating researchers will be able to use information from the Study to improve health services and programs for many health problems we face in later life, including cancer, cardiovascular disease, diabetes, mental health problems and arthritis.

To realise the full potential of the Study, particularly to develop new treatments and diagnostic tests, researchers from commercial companies may also be involved with the Study. All research projects will be in the public interest and have the potential to provide important information to improve health. They will also satisfy strict quality and ethical standards and again, no identifying information about participants will be released to collaborating researchers.

How will my health be followed over time if I agree to take part?

An important aspect of this study is observing your health over time and linking information you have given us in questionnaires with a number of other sources of information about your past, current and future health, medication, treatment and use of health services such as:

- hospital, pathology and death records; NSW Health and Department of Veterans' Affairs data; hospital waiting times, surgical procedures and emergency department information; ambulance services data and Roads and Traffic Authority information on accidents;
- Medicare and general practice information; Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme; aged care, mental health and hearing services information;
- special disease or treatment record systems, including diabetes and cancer registers; infectious diseases notifications; disability information; radiotherapy, injury, midwives and birth defects data; and dialysis and transplant register;
- breast, cervical, prostate and bowel cancer screening records.

Again, any information used from these data sources will be treated **completely confidentially and used for health research only**.

How can I find out more about the Study?

You can visit www.45andUp.org.au or call the Study helpline on **1300 45 11 45** to find out more and get regular updates on the Study's progress. People taking part in the Study will also receive a yearly newsletter.

Any questions or comments?

If you have any questions, comments or complaints about the Study, you can call the toll-free Study Helpline on **1300 45 11 45**

or write to:

Associate Professor Emily Banks
Scientific Director
The 45 and Up Study
PO Box 123
Broadway NSW 2007

For any complaints you may also contact:

Ethics Secretariat
The University of NSW
Sydney NSW 2052
Phone: (02) 9385 4234 or
Email: ethics.sec@unsw.edu.au

Support for the 45 and Up Study

“For years, older women and men have identified the need for exactly this sort of research to help understand our health needs. I will definitely take part in the Study myself and it has the blessing of the NSW Older Women’s Network.”

Betty Johnson, AO, Long term consumer advocate on health and ageing

“I am very excited that The Cancer Council will be able to play a key role in the 45 and Up Study. I believe the Study will provide a powerful resource for answering key questions about the causes of cancer and the factors that increase our risk, as well as effective treatments.”

Dr Andrew Penman, CEO, The Cancer Council NSW

“The Heart Foundation is proud to support the 45 and Up Study. This Study will assist us to improve the health outcomes for people living with, or at risk of, heart disease in NSW now and in the future. I am going to do my part to support the Study by joining up.”

Tony Thirlwell, CEO, National Heart Foundation of Australia (NSW Division)

“Health has always been important to me, but every year it seems to become more so. I’m very supportive of the 45 and Up Study as the best way we have of making sure people and governments can ensure better health in the coming years. I’ll certainly be joining up.”

Dr Denise Robinson, Chief Health Officer, NSW Health

“I am going to take part in the Study because it’s the first of its kind and we vitally need this information for long term planning for a very important sector of our community. By taking part, I feel I will be making an input based on my own experience. I was naturally concerned about privacy, anonymity and how the information will be used; however, I am very much reassured by the commitment to protect the use of these data.”

Irene Moss, AO, Formerly Commissioner, Independent Commission Against Corruption (ICAC) and NSW Ombudsman; Chair The Sax Institute Board.

“Rural residents are facing significant health challenges; understanding their health is vital both for this generation and generations to come. For this reason, I would encourage you to get involved in and support the 45 and Up Study. We need to do what we can to help ensure the health and longevity of rural Australia.”

Jock Laurie, President, NSW Farmers’ Association



For your records only

Here is a copy of the information contained in the Study consent form, for you to keep for your records

Consent Form

The *45 and Up Study* relies on the willingness of people in New South Wales 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* and for the Study team to follow your health over time. Participation is completely voluntary, and you are free to ask questions or to withdraw from the Study at any time, by calling the Study Helpline on 1300 45 11 45.

I agree to have my health followed over time through:

- the 45 and Up Study team following health and other records relating to me, including NSW hospital records, cancer records, death records and other health-related records, as outlined in the Study leaflet: *The 45 and Up Study: Information for participants*;
- Medicare Australia releasing to the 45 and Up Study my enrolment details, including Medicare number, and information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, until the end of the Study or for the duration of my involvement in the Study;
- being contacted in the future to provide information on changes to my health and lifestyle. I may also be asked to provide further information including questionnaire responses or biological samples; my participation in any of these would be completely voluntary.

I give my consent on the understanding that:

- my information will only be used for the purposes outlined in the Study leaflet entitled: *The 45 and Up Study: 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 the 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 Study at any time by calling the Study helpline on 1300 45 11 45;
- my decision on whether or not to take part in the Study 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 including how it will gather, store, use and disclose information about me, in the Study leaflet. I have been given an opportunity to ask questions and have been fully informed about the Study.

Name (Print):

Signature:

Date today:

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DO NOT SIGN
For your records only