

study

45 and Up Study

The 45 and Up Study is a long-term health study looking at ways to improve the prevention, diagnosis and treatment of a wide range of diseases such as cancer, heart disease, arthritis, diabetes, depression and Alzheimer's. Between 2006 and 2008, you were one of over 250,000 NSW residents aged 45 and over who joined the 45 and Up Study by completing a questionnaire about your health and lifestyle. More than 10% of the NSW population in this age group are participating, including having their health followed over time.

project

The Link-Up Project

The Link-Up Project is the next stage of the 45 and Up Study. The aim of the Link-Up Project is to collect further information from people like you who are already participating in the 45 and Up Study.

The Link-Up Project is not a separate study, but an extension of the 45 and Up Study. All of the information collected as part of the Link-Up Project will be linked to the information already collected by the 45 and Up Study, to make it an even more valuable contribution to health research.

Funding for the Link-Up Project has been generously provided by Cancer Council NSW.

benefits

Collecting updated health information, as well as blood samples and physical measurements, will allow the 45 and Up Study to conduct more in depth research into factors affecting healthy ageing. By looking at information, measurements and samples from participants, researchers will be better able to work out why some people develop particular diseases and others do not. This will help us to find new ways of preventing early death and disability from many different diseases. Like giving a blood donation, this next part of the 45 and Up Study may not directly help you or others who take part, but it will give future generations a better chance of living their lives free from diseases that disable and kill.



Link-Up Project Consent Form

The 45 and Up Study is designed to provide much needed information about how to stay healthy and independent throughout life. As one of over 250,000 45 and Up Study participants, you have already completed a questionnaire about your health and lifestyle. We are asking for your help again to give us updated information about your health, having your height, weight, waist, blood pressure and heart rate measured and giving a small blood sample. By signing this consent form you are agreeing to participate in the next stage of the 45 and Up Study, the Link-Up Project, as outlined in the participant information leaflet entitled 'The Link-Up Project: Information for Participants'. Participation in the Link-Up Project is completely voluntary and you may ask questions or withdraw your consent at any time by calling the 45 and Up Study helpline on 1300 45 11 45.

In signing this consent form, I agree:

- to the long-term storage and use of the information from my questionnaire and physical measurements for health-related research
- to the long-term storage and use of my blood sample, which I am donating to the 45 and Up Study, for health-related research
- to the 45 and Up Study combining the new information from the questionnaire, measurements and blood sample with the health information I have already given to the 45 and Up Study, as outlined in the participant information leaflet entitled 'The Link-Up Project: Information for Participants', of which I have a copy.

I give my consent on the understanding that:

- my information and blood sample will only be used for the purposes outlined in the participant information leaflet entitled 'The Link Up Project: Information for Participants'
- no results from my information or blood sample will be given to me or to my next of kin
- my information will be kept strictly confidential and will be used for health research only. Research, reports and publications from the 45 and Up Study will be based on de-identified information and will not identify any individual taking part
- my consent will continue to be valid following death or loss of decision-making capacity unless withdrawn by my next of kin or other person responsible. I may withdraw from the 45 and Up Study at any time by calling the 45 and Up Study helpline on 1300 45 11 45.
- my decision as to whether or not to participate in the Link-Up Project or any other additional research will not disadvantage me or affect my future healthcare in any way.
- I may be contacted again by the 45 and Up Study regarding future research – my participation in this will be purely voluntary.

I have read all of the above, as well as the information provided in the participant information leaflet entitled 'The Link-Up Project: Information for Participants'. I have been given the opportunity to ask questions and have been fully informed about the Link-Up Project. I agree to participate in the Link-Up Project.

NAME (PRINT)	
SIGNATURE	
DATE TODAY	
ADDRESS	

DO NOT SIGN
FOR YOUR RECORDS
ONLY

If you have any questions, please ring the **45 and Up Study helpline on 1300 45 11 45.**

You can also write (no stamp required) directly to:
Associate Professor Emily Banks, Scientific Director
The 45 and Up Study, Reply Paid 5289, Sydney NSW 2001

The Link-Up Project

Information for participants



In partnership with



Why you have been selected

Between 2006 and 2008, you were one of over 250,000 NSW residents aged 45 and over who joined the 45 and Up Study by completing a questionnaire about your health and lifestyle. We are now inviting 2,000 people from the 45 and Up Study who live near Parramatta or Wagga Wagga to participate in the Link-Up Project.

Your participation will assist us in deciding the best way of implementing the Link-Up Project before inviting more 45 and Up Study participants.

What we are asking you to do

We are asking you to:

- Complete a very brief questionnaire about current health (included with your invitation letter).
- Visit a health clinic in your area (at no charge to you).
- Give a small blood sample (less than two tablespoons/ 30ml) and have your height, weight, waist circumference, blood pressure and heart rate measured.

Taking of blood samples and measurements will be supervised by medical professionals. Feedback will be provided relating to your physical measurements but not in relation to your blood samples. The Link-Up Project is not a 'health check' and if you are concerned about any health issues for you or your family, please see your doctor or other health professional.

You will need to bring your completed questionnaire and consent form with you to your clinic visit.

We will provide updates

The 45 and Up Study will keep you up to date about how your information is being used through our Participant Newsletter. A full list of research projects that are underway is also available at www.45andUp.org.au

How we use the information and blood sample

The information and blood samples collected in the Link-Up Project will be linked to the health information you have already given to the 45 and Up Study and to information from your health and other records that you allowed the 45 and Up Study to access. These include NSW hospital records, cancer records, Medicare and other records (see www.45andUp.org.au or call **1300 45 11 45** for more information).

Your information and blood sample may be used within health research for:

- Approved research projects to investigate factors affecting the health of Australians in mid to later life.
- Looking at a very wide range of factors able to be measured in blood, such as cholesterol, antibodies, and blood sugars.
- Investigation of genetic factors, such as the structure and function of certain genes, and how they relate to a range of illnesses and other conditions.

In order to develop new treatments and diagnostic tests, it is also possible that researchers from commercial organisations may apply to use your information and blood sample. All research projects must demonstrate that they are in the public interest and have the potential to provide important information to improve health.

Results from physical measurements will be provided but **no results from your blood sample or other tests will be given to you or your doctor** (even if the results do not seem to be normal). This is because outside of a normal clinical setting this kind of feedback is of questionable value and may even be harmful (for example, causing undue alarm).

Your blood sample will generally not be analysed immediately following collection. Instead, over the next decades your sample will be stored securely and then analysed as needed for approved health research as part of the 45 and Up Study.

Our commitment to security and confidentiality

All information and blood samples provided to the 45 and Up Study are bound by Commonwealth and State privacy legislation and guidelines, including the *Health Records and Information Privacy Act* and the *NSW Health Privacy Manual*. Our commitment to providing a high standard in handling personal information includes:

- Working with the University of NSW Human Research Ethics Committee, which is responsible for overseeing the conduct of the Link-Up Project and the 45 and Up Study.
- Ensuring information is used for health research only.
- Ensuring your identifying information, such as name and address, is removed and stored separately as soon as possible.
- Ensuring information is not released in a way that would allow an individual or household to be identified, except as is compelled by law.

If you do not wish to take part

If for any reason you would like to decline taking part in the Link-Up Project we would be grateful if you could let us know by phoning the 45 and Up Study helpline on **1300 45 11 45** or emailing 45andUp@saxinstitute.org.au

If you require more information

We are able to answer your questions and respond to comments and complaints via our helpline on **1300 45 11 45** or you can visit our website www.45andUp.org.au

Alternatively, you can write to:
Associate Professor Emily Banks
Scientific Director
The 45 and Up Study
PO Box 123
Broadway NSW 2007

Complaints may be directed to:
The Ethics Secretariat,
University of New South Wales
Sydney NSW 2052
Phone: (02) 9385 4234
Fax: (02) 9385 6648
Email: ethics.sec@unsw.edu.au

Any complaint you make will be investigated promptly and you will be informed of the outcome.

The Link-Up Project