



PATH Through Life 60s+ Cohort Wave 6 Information Sheet and Consent Form

1. What is the research study about?

The PATH Through Life study aims to examine cognitive development and mental health from early to late adulthood. It tracks depression, anxiety, substance use and cognitive ability for the purpose of being able to examine their impact but also identify risk factors, as well as protective factors in the population.

This follow-up will be the 6th Wave of data collection for PATH participants, and we thank you for your involvement in the PATH project thus far. As the PATH 60+ cohort enters their 80s, the data collected will be particularly important for identifying age-related changes.

2. Who is conducting this research?

The study is being carried out by the following:

Principal Investigator: Professor Kaarin Anstey (Professor of Psychology, University of New South Wales; Senior Principal Research Scientist, NeuroScience Research Australia (NeuRA); and Honorary Professor, Australian National University)

Research Team: The PATH study team and interviewers are under the supervision of Professor Kaarin Anstey and are based at UNSW Canberra.

Research Funder: This research is being funded by the Centre of Excellence in Population Ageing Research (CEPAR), with National Health and Medical Research Council (NHMRC) funding.

IT support and services: ORIMA Research will be subcontracted by PATH to provide IT services and the online platform. This includes setting up a database with contact details, setting up a booking system, operating a Help Desk and processing the data.

3. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not want to take part in the study or this wave, you do not have to.

If you decide you want to take part in the research study, you will be asked to:

- read the information carefully (ask questions if necessary), then
- complete the consent form about participating in Wave 6.



4. What does participation in this research require, and are there any risks involved?

The study includes a phone interview conducted over two sessions; each session should take less than 45 minutes to complete. The phone interview will ask you about your health, psychological function, family situation, cognition, and lifestyle. At the end of your phone interview, you will also be invited to take part in an additional mail out survey.

As in previous waves, we will also seek your permission to contact a relative or close friend to ask them questions about your living situation, daily activities, health, memory, and thinking.

For this Wave, PATH has created an IT services arrangement with ORIMA Research. This means having some of your details temporarily stored by ORIMA for Wave 6 fieldwork. The risks of providing information to a third party are minimal given ORIMA's excellent data security systems.

5. What are the possible benefits to participation?

The PATH study has collected information over more than 20 years and continues to make major contributions to knowledge about mental health and wellbeing; this has only been made possible by involvement of each individual participant like yourself. The study overall and its findings have been and will continue to be used to produce research papers and inform understanding of the health and wellbeing in the Canberra community as well as national and international policy documents.

6. What are the possible risks to participation?

We do not expect the phone interview to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance. Alternatively, a list of services is provided in the contact details below to assist you if necessary.

7. What will happen to information about me?

Your data will be kept for a period of 7 years after the project's completion, and then permanently archived in a non-identifiable format.

By consenting below for the new IT services arrangement with ORIMA Research you are giving your permission for PATH to securely provide the following information to ORIMA solely for the purpose of supporting data collection for this Wave:

- your names (previous, maiden, first, last and preferred)
- your postal and mailing address
- your date of birth



- your emails (personal and work)
- your phone numbers (home, work and mobile)
- the date of your last interview
- Yes/No for participation in previous waves
- contact notes for Wave 6
- Wave 6 ID number
- previous interview date
- a copy of your consent and
- informant contact information (name, phone number, relation)

You are agreeing to ORIMA storing these details and any others you provide them, as well as hosting the questionnaires and booking details. Your information will not be used for any purposes other than for (i) updating your details, (ii) scheduling interviews, and (iii) collecting data. All PATH data provided to ORIMA will be deleted from ORIMA systems after the completion of Wave 6.

Storage of identifiable information

We will store your personal contact details in a secure, access restricted encrypted database located on UNSW local servers located in Sydney. This personally identifiable data includes your contact details, PATH identification number and your participation in waves and sub-studies.

If you provide consent, ORIMA Research will also have a subset of your identifiable information during Wave 6 but will not have your PATHID. ORIMA Research will store this information on an online database hosted in Australia by Zettagrid Australia, an Australian Government endorsed supplier with encryption and protection by a firewall. ORIMA will delete this information at the end of Wave 6.

Storage of unidentifiable information

For ORIMA Research IT services, during data collection we will store information about you in an unidentifiable format (i.e. survey responses). ORIMA Research will store this information on an online database hosted in Australia by Zettagrid Australia. ORIMA will delete this information at the end of Wave 6.

Following data collection and cleaning, we will store electronic information about you in an unidentifiable format at the ANU in secure servers. We will also store a copy on UNSW servers which is encrypted and has access restricted to study staff.

Your unidentifiable information will be used by PATH Executive Committee approved researchers and published in journal articles, research papers, presentations, etc. Information collected for this research project may also be made available to other research projects in de-identified form only.



Your identifiable and unidentifiable data will be kept separate, and not stored in the same location.

8. How and when will I find out what the results of the research study are?

You can find information about the results of the studies and publications on the PATH website: <https://pathstudy.org.au>. All information is published using summary statistics that do not identify individuals. You may also request information about the study by contacting the PATH Project Manager Tanya Price on info@pathstudy.org.au or call the PATH number on 1300 917 295.

9. What if I want to withdraw from the research study or this wave?

You may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Or, you can phone or email the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study, will not affect your relationship with UNSW Sydney, ANU, or any of the organisations that provided funding or support for the study.

The information you provide is personal information for the purposes of the Privacy Act 1988 (Cth) and the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the universities, the right to request correction and amendment of it, and the right to make a complaint about conduct that may be an interference with your privacy. Further information on how the University protects personal information is available in the UNSW Privacy Management Plan.

10. What should I do if I have further questions about my involvement in the research study?

If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact

Name	Tanya Price
Position	PATH 60s+ Wave 6, Project Manager
Telephone	1300 917 295
Email	info@pathstudy.org.au



What if I am distressed and need support?

If at any stage during the study you (or your contact/relative who is answering questions about you) become distressed or require additional support from someone not involved in the research, please call:

Contact for feelings of distress

Name/Organisation	Beyond Blue
Telephone	1300 22 4636 (24 hours, 7 days a week)
Website	https://www.beyondblue.org.au/

Alternatively, please contact the PATH office for a list of additional support services.

What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC200430



Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet or it has been provided to me in a language that I understand;
- I provide my consent for the information collected about me to be used for the purpose of this research study only;
- I understand that my contact information will be shared temporarily with ORIMA Research for the purpose of the wave under the current arrangement with PATH, and will be deleted at the end of the wave;
- I have informed my informant contact person that I have nominated them and given their phone contact details to UNSW/ORIMA for the purpose of this wave;
- I understand that if necessary I can ask questions and the research team will respond to my questions;
- I understand that I am free to withdraw at any time during the study or decline participating in this wave of the study and this will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form <https://pathstudy.org.au>.

Participant Details

Name of Participant (please type)	
Participant date of birth	
Date	



Informant Contact Details

Once again, we would like to contact a relative or close friend who has known you well, ideally, for the last ten years. If you do not have a contact person who has known you for at least ten years, then someone who has known you well for at least a few years would be fine. Most of you have previously provided details of this contact person and your interviewer will have this information.

Consent to contact informant

- I am willing to have the person indicated below contacted at this wave (2020).
- I am willing to have the person indicated below sign a PATH interview consent form on my behalf at a future time, if I am unable to do so but willing to do the interview.

If the person to contact is NOT the same person you gave details of at your last interview, please provide the contact information in the box below.

New contact (relative or close friend)	
Name:	
Relationship to you:	
Home phone number:	
Work phone number:	
Mobile number:	
Age group:	<input type="radio"/> Under 65 years <input type="radio"/> Over 65 years
Length of time you have known each other:	



Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, ANU or any organisation that supports the PATH Through life Project. In withdrawing my consent:

Please Indicate here which of the following two options you would like to happen with your data:

A. I would like to withdraw from the study but agree to leave my research data from prior participation in the study dataset in de-identified format. I understand my contact details will be deleted from the study database.

Yes

OR

B. I would like any information which I have provided for the purpose of this research study withdrawn.

Yes

Participant Name

Name of Participant	
Date	