**PATH Through Life Study 40s Cohort**

1. **What is this information sheet about?**

My name is Professor Kaarin Anstey and I was previously at the ANU and have recently moved to UNSW. You are currently a participant in the PATH Through Life study. The purpose of this communication is to tell you about changes to the PATH study team, their institutional affiliation, and new data storage arrangements. We also seek your consent to remain a participant in the PATH Through Life study. Agreeing to continue in the study will allow us to contact you about taking part in future Waves of data collection. If you agree to continue we would also like to invite you to participate in Wave 5 of the PATH project that will commence in 2019.

1. **Who is conducting this research?**

The next wave of the PATH study is being carried out by the following researchers:Professor Kaarin Anstey, Honorary Professor in the Research School of Population Health, Australian National University and Professor in the School of Psychology at the University of New South Wales, and Neuroscience Research Australia**.** The ANU and UNSW have established a PATH Governance Committee and Research Committee to oversee the effective operation of the research and ensure security of the PATH Data.

**Research Funder:** This research is being funded by the ARC Centre of Excellence in Population Ageing Research (CEPAR).

For this Wave, you have the option of agreeing to PATH’s IT services arrangement with ORIMA Research. ORIMA is 100% Australian owned company and is Australia’s largest provider of research services to the Australian Government. This means having some of your details temporarily stored by ORIMA for Wave 5 fieldwork and accessing the ORIMA IT platforms to book and complete questionnaires and interviews. You will receive emails from ORIMA and access IT platforms they have set up. You may also call an ORIMA-based IT Help Desk for assistance completing your questionnaire or arranging a booking.

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

Your participation in the PATH study is voluntary, and you may decline to take part in specific parts of the study or withdraw from the PATH study without providing an explanation at any time.

 If you decide to withdraw from the PATH study, your contact details will be destroyed from the PATH databases. Summary statistics derived from your datasets including your data that are published cannot be changed, but you may request removal of any previously collected identifiable data from datasets available to researchers. If you do not want to take part, you do not have to.

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

The study includes an on-line questionnaire and face to face interview.

 The online questionnaire will ask you about your health, psychological function, family situation, and lifestyle. In the online survey you will be asked about your use of alcohol and drugs. Any information you provide will remain confidential, and will be protected to the extent permitted by law. PATH does not offer intervention for alcohol or drug use, but interviewers can provide contact details of support services.

The face to face interview for Wave 5 is similar to previous waves. It requires you to meet with a PATH Interviewer at your home or other suitable location, and complete physical assessments of your height, vision, grip strength, memory and thinking skills and decision-making capabilities. You can stop the interview at any time.

1. **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

1. **What are the possible risks?**

We do not expect the questionnaire or face to face 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.

1. **What will happen to information about me?**
* PATH Researchers will continue to store your personal contact details in a secure, access restricted servers. They will be located on servers at ANU and UNSW which are managed by ANU and UNSW IT services. The personal contact details will only be used to carry out the survey and keep you informed through emails and Newsletters.
* Your de-identified research data will be stored in a secure institutional repository at ANU and a copy of the research data will be held at UNSW.
* the PATH research team and other collaborators (approved by the PATH Research Committee) will use your research data for conducting research into mental health, cognitive function, lifestyle, wellbeing and healthy ageing. Information collected for this research project may be made available to other research projects in de-identified form only.

Each new wave of data collection will specifically seek your informed consent for taking part in that wave. Consenting to remaining in the PATH study does not mean that you automatically consent to taking part in future waves of data collection. Any information you provide will remain confidential as far as the law allows.

In order to efficiently carry out the study we have engaged ORIMA Research to provide on-line services to support the on-line questionnaire and interviewing. If you provide your consent to using ORIMA’s services, 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 5
	+ Wave 5 ID number and
	+ a copy of your consent

If you consent for the above to take place, then you are also 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) obtaining and verifying your consent, (ii) updating your details, (iii) scheduling interviews and survey access, (iv) collecting data. 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 5.

Your identifiable information will only be used for the duration of the PATH study; to keep in contact with you, manage your participation in the study, update you of results and ensure your survey responses at each Wave are linked.

**How long:** Due to the nature of this project being a longitudinal study, your identified data will be kept for a period of 7 years after the final waves’ completion, and then permanently archived in a non-identifiable format.

1. **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 (tanya.price@unsw.edu.au) or info@pathstudy.org.au.

1. **What if I want to withdraw from the research study?**

You may withdraw at any time. You can do so by completing the ‘Withdrawal of Consent Form’ which is provided online. Or, you can phone or email the research team and tell them you no longer want to participate.

If you decide to leave the research study, the researchers will ask you if you agree that the data collected to date be retained or if you would like your prior identifiable information destroyed. If you do then we will destroy any identifiable information that has already been collected and no additional information will be collected from you. If you want to withdraw but do not want your identified prior information destroyed you may agree to leave your data in the PATH dataset. 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](https://www.legal.unsw.edu.au/compliance/privacy/unsw_pmp.pdf) and <https://policies.anu.edu.au/ppl/document/ANUP_010007> on the ANU website.

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

 The person you may need to contact will depend on the nature of your query. 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 UNSW*

Name: Tanya Price

Position: PATH Project Manager

Telephone: 1300 917 295

Email: tanya.price@unsw.edu.au

**Contact Details if in Distress:**

 If at any stage during the study you become distressed or require additional support from someone not involved in the research, please call:

*Contact for feelings of distress*

Name/Organisation: Lifeline

Telephone: 131114 (24 hours, 7 days a week)

Website chat support: <https://www.lifeline.org.au/get-help/online-services/crisis-chat>

**Ethics Committee Clearance:**

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (HREC) (Protocol 2010/542) and UNSW HREC (HC180518). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager
The ANU Human Research Ethics Committee
The Australian National University
Telephone: +61 2 6125 3427
Email: Human.Ethics.Officer@anu.edu.au

Human Research Ethics Coordinator

The UNSW Human Research Ethics Committee
The University of New South Wales
Telephone: +61 2 9385 6222
humanethics@unsw.edu.au

WRITTEN CONSENT for Adult Participants

**PATH Through Life Study**

Thank you for participating in the PATH study to date. The study continues to provide valuable information on mental health, cognitive function, lifestyle, wellbeing and healthy ageing with benefits to the Canberra Community and beyond. We have provided a detailed information sheet describing the changes to the study following the move of Professor Anstey to UNSW and for undertaking Wave 5. We now seek your consent as laid out below.

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I have read and understood the Information Sheet you have given me about the research project, and I have had any questions and concerns about the project addressed to my satisfaction.

In order to continue in the PATH Study you can either consent to points 1-4 below to participate on-line by clicking on the **I agree button for continuing in PATH.** You can then decide whether you wish to participate electronically in the study through an on-line questionnaire by clicking on the **I agree button to working on-line with ORIMA.**

**Alternatively, you can consent manually by completing the form below** and return the form to

Ms Tanya Price

PATH Through Life Study

Building 36, UNSW Canberra at ADFA

PO Box 7916

Canberra BC ACT 2610

If you do not wish to continue to participate you should complete the withdrawal of consent form.

|  |  |
| --- | --- |
| 1. I agree to continue to participate in the PATH study as a multi-institutional project and for the PATH team from ANU or UNSW contacting me in the future to participate in waves and receive email updates and newsletters.

 As part of this I agree to the revised data storage arrangements with PATH Researchers storing my personal contact details in secure, access restricted servers. They will be located on servers at ANU and UNSW which are managed by ANU and UNSW IT services.  | YES ☐ NO [ ] (If NO, please proceed to Withdrawal of Consent form) |
| 1. I agree to participate in PATH WAVE 5 as a multi-institutional project and to participate in the on-line questionnaire and interview.
 | YES ☐ NO [ ] (If NO, please proceed to question 4) |
| 1. During this wave:
 | ☐ I agree to the new IT service and support arrangement with ORIMA Research for Wave 5.OR☐ I agree to participate in the PATH study Wave 5 without the engagement of ORIMA. |
| 1. I agree to:
* the PATH research team and other collaborators using research data (the research data is identified by an ID number only) for conducting research into mental health, cognitive function, lifestyle, wellbeing and healthy ageing.
* research data that doesn’t contain my name or personal contact details being made available to other research projects
 | YES ☐ NO [ ]  |

Signature:…………………………………………….

Date:………………………………………………….

**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 any information which I have provided for the purpose of this research study withdrawn.

|  |
| --- |
| **Yes** |

OR

**B.** 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** |

**Participant Name**

|  |  |
| --- | --- |
| Name of Participant |  |
| Date |  |