

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

ARC Experience and Empathy Laboratory
Phenomenological and Embodied Experience Associated with Ageing in Older Adults
Professor Jill Bennett (Chief Investigator)

1. What is the research study about?

You are invited to take part in this research study. The research study aims to interview older adults aged between 60 – 95 years of age. These interviews will allow the researchers to learn more about how older adults perceive ageing and how they are personally experiencing the ageing process, including any changes they may have noticed in their own brain functioning over time. We hope to learn more about how older adults experience ageing and how it affects every aspect of their life including how they see, feel and think. You have been invited because you are an older adult who has indicated you are interested in participating in research and your contact details were provided by you when you responded to our study recruitment advertisement.

2. Who is conducting this research?

The study is being carried out by the following researchers: Professor Jill Bennett (Chief Investigator), Dr Christopher Papadopoulos (Associate Investigator) and Dr Natasha Ginnivan (Associate Investigator) from the National Institute for Experimental Arts (NIEA) which is part of UNSW Art & Design.

Research Funder: This research is being funded by an Australian Research Council Australian Laureate Fellowship.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking to recruit people who meet the following criteria:

Inclusion Criteria:

- 60 to 95 years old
- Living in Sydney
- Proficient in English
- Willing and able to participate in semi-structured interviews
- Recent diagnosis of dementia, Mild Cognitive Impairment (MCI) or cognitive functioning within the normal range
- Able to provide written informed consent

Exclusion Criteria:

- Unable to provide written informed consent

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

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

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);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

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

If you decide to take part in the research study, you will be asked to participate in up to three face to face interviews. You will be asked questions about your personal experiences of ageing, including any changes that you may have experienced related to ageing. It should take approximately 45 minutes – 1 hour to complete an interview.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. If you would like to participate but do not wish to be audio recorded, you

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will need to discuss the options for your participation with the research team. We would also like to video record some interviews, however, this is optional and would only be for the second and/or third interviews.

The following is a summary of each face to face interview:

1. Interview 1: The first interview will take place at the University of New South Wales Paddington campus. This will provide the researcher an opportunity to introduce themselves and for the participant to begin telling their story about their personal lived experience of the ageing process. A short cognitive screening task (described below) will be administered at the end of the interview.
2. Interview 2: If you agree to a second interview, this will provide you an opportunity to go into greater detail about your lived experience of ageing. The second interview will take place either at the University of New South Wales Paddington campus, your home (only with your consent) or a place where you feel comfortable (e.g., a local park) depending on your preference and what is appropriate. The researcher may also ask for the interview to be video recorded to obtain a more detailed record of your story, however, this is optional and requires your consent.
3. Interview 3: If you agree to a third interview this would be a final opportunity to provide further detail about your experience of ageing in the context of this research study. The location and details (e.g., whether this interview will be video recorded) will be discussed and your consent requested in the same way as for the previous interviews.

We don't expect the questions 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, the contact details for Lifeline – a free crisis support telephone service available 24/7 – are provided below. Lifeline can be contacted when feeling distressed.

If you decide to take part in the research study, the research team we will also ask you to complete a short screening of cognitive functioning which is administered by a member of the research team and consists of a series of questions testing various cognitive domains such as memory and language. It should take approximately 10 – 15 minutes to complete this task. This task will be conducted at the end of the first interview– the total time for the interview and screening task will still be approximately 1 hour.

We don't expect the cognitive screening task 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.

6. Will I be paid to take part in the research study?

Participants will be eligible for a one-off \$100 Coles voucher

Research Team Contact Details

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|-------------|--------------------------|
| Name | Christopher Papadopoulos |
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PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

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|------------------|--|
| Position | Postdoctoral Research Fellow |
| Telephone | (02) 8936 0512 |
| Email | c.papadopoulos@unsw.edu.au |

| | |
|------------------|--|
| Name | Natasha Ginnivan |
| Position | Postdoctoral Research Fellow |
| Telephone | (02) 8936 0511 |
| Email | n.ginnivan@unsw.edu.au |

7. What are the possible benefits to participation?

We hope that participation in this study provides an enjoyable and insightful opportunity to talk with researchers about your own lived experiences of ageing and any changes you may have noticed in your own life related to ageing. We also hope to use information we get from this research study to benefit others who wish to better understand the ageing process. By gaining a greater understanding of the personal lived experience of ageing we hope to improve the overall understanding that society has about ageing and decrease negative beliefs related to ageing.

8. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your data will be kept for a minimum of 7 years after the project's completion. Audio and video recordings of the interviews will be transcribed by a member of the research team. We will store information about you in a non-identifiable format for the interview transcripts and results of the cognitive screening task. The audio and video recordings may contain identifiable information. Information about you will be securely stored at the University of New South Wales Paddington campus in a locked cabinet (hardcopy data sources) and on a password protected computer network (digital data sources) only available to members of the research team.

Researchers at UNSW are required to store their any aggregated data in the UNSW data repository, this is a system called ResData. Once the aggregated data is deposited into this repository it will be retained in this system permanently. It will, however, be retained in a format where your identity will not be known.

Your information will be used for scholarly publications and/or conference presentations in such a way that you will not be individually identifiable. De-identified information may also be used for exhibitions at art galleries, libraries or museums. Information where you could be identified such as a video recording would only be used with your consent and would only be used for scholarly purposes such as an exhibition at an art gallery, library or museum.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

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

The research team intend to publish and/or report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you.

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

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If you would like to receive a copy of the results you can let the research team know by adding your email or postal address within the consent form. We will only use these details to send you the results of the research.

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

If you do consent to participate, 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. Alternatively you can ring 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 or the Australian Research Council.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

The research team will destroy any information about you that was collected during your participation in the study.

11. 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 Details

| | |
|------------------|--|
| Name | Christopher Papadopoulos |
| Position | Postdoctoral Research Fellow |
| Telephone | (02) 8936 0512 |
| Email | c.papadopoulos@unsw.edu.au |

| | |
|------------------|--|
| Name | Natasha Ginnivan |
| Position | Postdoctoral Research Fellow |
| Telephone | (02) 8936 0511 |
| Email | n.ginnivan@unsw.edu.au |

Support Services Contact Details

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

| | |
|---------------------|----------|
| Organisation | Lifeline |
| Telephone | 13 11 14 |

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 | UNSW Human Research Ethics Coordinator |
| Telephone | + 61 2 9385 6222 |
| Email | humanethics@unsw.edu.au |
| HC Reference Number | HC180385 |

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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 someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- I understand that the research team will audio record the interviews; I agree to be recorded for this purpose.
- I understand that the research team may also request to video record one or more of the interviews; I agree to be recorded for this purpose.
- I provide my consent for the research team to administer a short cognitive screening task for the purpose of screening participants on the basis of cognitive functioning for the research study.
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

Name: _____

Address: _____

Email Address: _____

- I understand that I will be given a signed copy of this document to keep;

Participant Signature

| | |
|------------------------------------|--|
| Name of Participant (please print) | |
| Signature of Research Participant | |
| Date | |

Declaration by Researcher*

- I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

| | |
|-----------------------------------|--|
| Name of Researcher (please print) | |
| Signature of Researcher | |
| Date | |

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.

UNSW Art & Design
National Institute for Experimental Arts



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, and any member of the research team. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

Participant Signature

| | |
|---------------------------------------|--|
| Name of Participant (please print) | |
| Signature of Research Participant | |
| Date | |

The section for Withdrawal of Participation should be forwarded to:

| | |
|-----------------|---|
| CI Name: | Professor Jill Bennett |
| Email: | j.bennett@unsw.edu.au |
| Phone: | (02) 8936 0691 |
| Postal Address: | National Institute for Experimental Arts, UNSW Art & Design, PO Box 259, Paddington, NSW 2021 |