

The Resilient Minds (ReMind) Longitudinal Project Scientia Professor Kaarin Anstey

## 1. What is the research study about?

You are invited to take part in this research study. This study aims to understand changes in psychological resilience and cognitive function. The study uses a smartphone app and smart watches. People who choose to participate will complete questionnaires and short game-like tasks through their iPhones and will receive an Apple Watch (if available) to use during the study.

### 2. Who is conducting this research?

- The study is being carried out by the following researchers:
- Scientia Professor Kaarin Anstey, Professor in the School of Psychology at the University of New South Wales (UNSW)
- Dr Brooke Brady, ARC Postdoctoral Fellow at the UNSW Ageing Futures Institute
- Dr Lidan Zheng, ARC Postdoctoral Fellow at the UNSW School of Psychology
- Dr Ranmalee Eramudugolla, Research Manager at the UNSW School of Psychology
- Daniel Ashworth, Senior iOS developer at the UNSW Ageing Futures Institute
- Tanya Layton, Project Manager at the UNSW School of Psychology
- Dr Hamidul Huque, Statistician in the UNSW School of Psychology
- Jana Koch, PhD Student at the UNSW School of Psychology
- Shally Zhou, PhD Student at the UNSW School of Psychology

Research Funder: This research is being funded by the Australian Research Council and Apple Inc. provided a limited number of smart watches used in this project.

#### 3. Inclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. We are looking recruit people who are:

- Adult volunteers living in Australia
- Between the ages of 18-95 years
- Proficient in English
- Able to use an iPhone without assistive technology (e.g., having your phone read out text)
- Willing to give informed consent, follow study instructions and participate in a longitudinal (long-term) study
- Current iPhone users and willing to use your iPhone to download a free UNSW research application
- Able to access to a home Wi-Fi connection for the time of the study
- Preferred: willing to wear the Apple watch and use earphones to complete hearing tasks if eligible and available, both devices are provided for you to use during the study

#### 4. 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, you do not have to.

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

- Read the information carefully and ask any questions.
- Complete the consent form in the research app.
- Participate in various surveys and game-like tasks in the app.
- Wear an Apple watch (if available) to collect passive health and environmental data.

# 5. What will I do in this research study and are there any risks?

Our study uses this app to send you questionnaires and short game-like tasks. Surveys ask about your health, cognitive, lifestyle and perceptions of ageing and gender. Active tasks will measure your cognitive, physical, and sensory function. These tasks are quick and may even be fun!



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# Baseline and follow-ups

The baseline and two annual follow-ups will take around 2 - 3 hours to complete. They have a longer health questionnaire and app-based tasks. You can complete activities in your own time, but we prefer if you do them on the same day. You can do the tasks in blocks or all at once.

#### Sprints

Regular tasks and questionnaires take less than 10 minutes per day to complete. These questionnaires will only occur as 7-day 'sprints' throughout the study. There are 4 themes for the sprints, and one is released every 2-3 months. For example, we ask about your feelings over a week to learn about how mood fluctuates day-to-day. We may add sprints in response to major events such as natural disasters. We will only do this with ethical approval.

#### Reminders

Throughout the study, the app will send reminders when activities are available. You can change the notification settings within the app.

#### Study length

The study is funded for two years, but we hope to collect data beyond this. We will ask if you want to continue participating if we extend the study. We may also contact you during the study to check if you need help or have any questions.

#### Sub-study on environment and resilience

One of our aims is to investigate how our environment (e.g., neighbourhood and other frequently visited places) may impact resilience, memory and thinking. To do this, we are seeking funding for a sub-study on 'Environment and Resilience.' We would examine the attributes of your neighbourhoods and other visited locations. Features include traffic-related air pollution and noise, availability of services and quality of footpaths. If that sub-study is approved, we will ask for your consent in the study app.

#### Other sub-studies

Some participants will be invited into other sub-studies throughout the project. For example, a substudy that examines biomarkers and involves a brain scan. These sub-studies are entirely voluntary. If you are invited, your decision to participate will not impact the main study.

#### Internet and mobile data usage

The research app needs an internet connection to download and use. There may be extra network costs if you are on a limited internet or phone data plan. However, the data usage is minimal (expected to be less than 100 KB on a typical day). The app needs around 100 megabytes to install and will use up to 200 megabytes over the 2-year study period.

#### **Study devices**

If eligible and available, we will send you earphones to use in some tasks and an Apple Watch to wear during the research study. The earphones are for audio tasks and the Apple Watch collects information on physical activity, sleep, heart rate and exposure to noise in the environment. It does this using in-built sensors to measure movement, heart rate, and location. A microphone measures environmental noise but does not take any recordings. Without the Apple Watch, you may not be eligible for certain sub-studies. During the study, we may collect location data (e.g., approximate home location, range of daily travel) in one-week intervals. The app will ask if the following week is suitable before collecting location data. The watch cannot record any personally identifying information about you such as messages or calls.



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Participants are able to use their own Apple Watches and earphones to participate in the study.

# Permissions

The Apple Watch connects to your iPhone through Bluetooth and Wi-Fi. This research app requests permission to access the following health data from the Health app: energy usage, activity, sleep, heart rate, noise exposure and mobility.

This research app can only access information that's been requested from your smartphone. You can also review or change your permissions at any time via your phone settings.

See the info section of the app for how to do this.

#### Caring for the Apple Watch

Please keep the watch clean and dry, especially after it has had contact with any liquids like sweat, soap, lotions, and sunscreen. This is to prevent skin irritation and damage to the watch. Wearing the watch too tightly or loosely may cause irritation or rubbing. *Apple Watch is a trademark of Apple Inc., registered in the U.S. and other countries and regions.* 

#### Need help?

If you experience discomfort or feelings of distress while completing the study, you can stop participating at any time. You can also contact the research team and they will assist you. Otherwise, section 10 and the info section in the app has the contact details of support services.

#### 6. What are the possible benefits to participation?

The information gathered from the study will allow us to gain insights into how psychological and cognitive resilience changes over time, and the personal characteristics and environmental factors that can influence these changes.

You will be able to see information about your health and physical activity in real-time using the Apple watch which may be of interest to you.

You will also be able to use other Apple watch features such as answering phone calls, text messages and setting alarms. You will be able to use the Apple watch for the duration of the study but will need to return the Apple watch to the researchers at the end of the study.

#### 7. 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 identifiable data will be kept in a separate database for 5 years after the conclusion of the study. Your study information will be stored in a de-identified format where any identifiers such as your name, address, date of birth will be replaced with a unique code. Information collected from you through the app will be stored on a UNSW password-protected OneDrive. The de-identified study data will be kept indefinitely to allow for reuse and data sharing in future studies. The data can be deleted after at least 15 years when the researchers deem it unnecessary to retain it for longer. The data is only accessible to the investigators listed at section 2 of this document. Apple may also request de-identified aggregate study data collected from Apple watches used in this project.

Other researchers may request to access the de-identified data in the future. Data will only be shared if researchers agree to protect the privacy of the information. Their access will also require approval from the ReMind research team and approval from a Human Research Ethics Committee (HREC). All information shared will be de-identified using participant ID codes. Researchers can only access the study data essential to their research.



As part of the consent form, you will be asked if you wish to be contacted for other future research opportunities. This is completely voluntary and if you consent, you will be required to provide your contact details (name, email, phone number, and address). Your contact details will only be accessible by our research team and will not be shared with other researchers. Your contact details will be similarly stored on secure servers for a minimum of 5 years. After 5 years, you may be contacted to re-consent to keep your information on the database.

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 <u>UNSW</u> Privacy Management Plan.

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

The research team intend to report the results of the research as internal documents, journal articles, and conference presentations. All information will be published in a way that will not identify you. Publications will report on group averages and data will not be retraceable to individual participants. Participants can also stay up to date with study results on the study website: https://unsw.to/resilientmindstudy.

#### 9. 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, withdrawing via the mobile research app itself, or you can contact 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 any of the researchers involved in this study.

#### 10. 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:

Name	Tanya Layton	
Position	Project Manager	
Telephone	0497 732 665	
Email	ResilientMinds@unsw.edu.au	
Name	Prof Kaarin Anstey	
Position	Chief Investigator	
Telephone	(02) 9399 1019	
Email	ResilientMinds@unsw.edu.au	

#### **Research Team Contact**

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



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# Contact for feelings of distress

Name/Organisation	Lifeline
Telephone	13 11 14 (24 hours, 7 days a week)
Website Chat Support	https://www.lifeline.org.au/get-help/online-services/crisis-chat

## 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 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	HC220273



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# Consent Form – Participant providing own consent

# Declaration by the participant

By checking the I agree/start questionnaire option below:

- □ 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 understand the purposes, study tasks and risks of the research described in the study.
- □ I understand that the research app requires an internet connection and that may mean additional network costs if I am on a limited internet or phone data plan.
- I understand that if I choose not to share any Apple Watch data, I might not be eligible for certain substudies;
- □ I understand that Apple has funded the smartwatches provided in this project and that Apple may access de-identified study data collected from these devices.
- I understand that the app will request permission to collect de-identified health and environmental data (e.g., daily steps, heart rate, sleep, environmental noise, location data). I consent to having this deidentified data being collected and summaries being used for the study.
- □ I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- □ I understand that this is a longitudinal research study and I agree to be contacted in the future regarding additional waves of data collection and future sub-studies.
- □ 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 agree for my study data to facilitate future research; I understand that my study data will be made available to other researchers, but my identity will be protected, and my confidentiality will be preserved.
- □ I understand that I can view and download a signed copy of this document through the app.

Optional consent:

- □ I consent to wearing an Apple watch and understand that if I am given an Apple Watch for the duration of the study, it is to collect health and environmental data. I consent to sharing the health and environmental data requested through the app
- I consent to my name and contact details being retained by the Research Team in a secure server so
  I can be contacted about future research opportunities
- □ I consent to be contacted by the Research Team about participation in media events

# **Participant Signature**

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



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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. I wish to withdraw my consent for:

- □ Sharing de-identified Apple Watch data only but would like to continue with other surveys and questionnaires in the study.
- □ the study entirely

In withdrawing my consent, I would like any information which I have provided for the purpose of this research study to be (select one):

- Retained in the data set for research purposes
- □ Completely withdrawn from the study

#### Participant Signature

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

#### The section for Withdrawal of Participation should be forwarded to:

CI Name:	Scientia Professor Kaarin Anstey
Email:	ResilientMinds@unsw.edu.au
Postal Address:	School of Psychology UNSW Australia UNSW Sydney NSW 2052 Australia