UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

PARTICIPANT INFORMATION SHEET

1 Title of study

Everyday Memory Failures and The Use of Memory Strategies in Healthy Ageing and Mild Cognitive Impairment: A Diary Study.

2 Introduction

You are being invited to take part in a study. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information.

1 What is the purpose of this study?

This study is about memory and ageing. While age related memory impairments have often been documented in laboratory tasks, it is unclear to what extent these findings generalize to real life settings. Indeed, very little is known about ageing and everyday memory failures or what kind of memory strategies people use to overcome their memory errors in everyday life. Preliminary findings, for example, suggest that people vary greatly in the frequency of reported memory errors, irrespective of age, with some participants showing preserved cognitive functioning well into old age. Even less information is available about how people compensate for memory failures in their day-to-day life.

These questions are particularly important for older adults who live independently as well as for people who have been diagnosed with Mild Cognitive Impairment. Therefore, this new project will use a novel and comprehensive approach assessing memory and compensation strategies in everyday life using several questionnaires and asking participants to keep two diaries: one for recording everyday memory failures and one for recording the use of memory strategies. The results will help us to gain a better understanding of nature and frequency of memory failures in everyday life as well as strategies people use to help with everyday memory tasks. It will also enable us to compare everyday memory functioning in healthy young and older adults and older adults with Mild Cognitive Impairment.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

5 Are there any age or other restrictions that may prevent me from participating?

Anyone between ages 18-35 and 60-89 can participate in this study. In addition to this, certain condition will prevent you from participating in this study. These are: previous head/brain injury; stroke; recurrent alcohol abuse or dependency; mental health problems (diagnosed by a doctor), and memory problems (diagnosed by a doctor).

6 How long will my part in the study take?

If you are willing to take part, we will have initial brief telephone conversation to confirm that you satisfy our initial screening criteria. If you do, you will be asked to meet with the researcher at her office at University of Hertfordshire or at your own home three times over a two-week period. We will also have two brief telephone conversations.

7 What will happen to me if I take part?

In our first meeting (lasting up to 2 hours), you will complete several questionnaires about your mood, daily living and memory. You will also complete some simple memory and attention tasks, such as remembering a list of words, remembering a short story, connecting a set of dots, and copying a figure. At the end of the session, you will be asked to keep a small diary booklet for 3 days. Every time you experience a memory failure (e.g. can't remember something), you will have to complete a brief 5-item questionnaire on a diary page. Each recording would only take 1-2 minutes. Detailed instructions about how to keep the diary will be provided. To help you with the diary task, you will be given a plastic waterproof wrist watch, to wear for 3 days, that will remind you several times a day to keep recording memory errors in the diary. There are no set expectations about how many memory failures you will record, as people vary greatly in this respect, with some recording very few and others recording many.

The second face-to-face meeting (lasting up to 30-45 min), will take place approximately 7-8 days from the first meeting. In this meeting, you will hand in the diary of everyday memory failures and complete a couple of questionnaires. You will then receive detailed instructions about how to keep a 3-day diary of memory strategies that you use in your daily life. Every time you use a memory strategy (e.g. make a shopping list, refer to a calendar, use mental rehearsal, etc.), you will have to complete a brief questionnaire on a separate diary page. As before, each recording would take only 1-2 minutes, and you will be asked to wear a plastic wrist watch reminding you to keep recording in the diary for 3 days.

In the final meeting (lasting up to 20-30 min), you will hand in the diary of memory strategies and return a wrist watch. You will also complete a questionnaire about your memory and strategy use. You will also have an opportunity to discuss your experience of taking part in this study and provide feedback about any aspect of the study.

In addition to these face-to-face meetings, you will receive a couple of brief telephone calls from the researcher (each lasting about 10 min), after you finish keeping each of the diaries. During these phone calls, you will be asked few questions about your experience of keeping a diary and the date for the next meeting will be agreed.

8 What are the possible disadvantages, risks or side effects of taking part?

Completing memory tasks and keeping diary present minimal risk to you. In addition to this, you may withdraw from the study at any time. The researcher will check on your welfare throughout the study as your comfort and wellbeing are very important.

As this is a research study, looking at the average performance across the groups, we are unable to provide you with feedback on your performance. However, in the unlikely event, that your test scores are lower than expected for your age group, it is our duty to inform you about it and advise you to contact your GP for further, more formal assessment. We will inform you only, if you have agreed for us to do so in the consent form.

If following this study you feel distressed in any way, please speak to a member of the research team or your GP. If you feel distressed during out of normal office hours (5pm till 9am) please contact NHS Mental Health Helpline on **01438 843322**.

9 What are the possible benefits of taking part?

By taking part in this research you will help to improve the understanding of memory failures in everyday lives of healthy adults and how they differ from those experienced by people with Mild Cognitive Impairment. Information about the use of memory strategies will also be valuable in understanding to what extent they are used in everyday lives and how helpful they are.

10 How will my taking part in this study be kept confidential?

Any information you provide will only be used for the purposes of this study and your data will be

treated confidentially and be anonymized. Any personal details will be kept safe, secure and separate from the research data. Information you provide will only be accessible to the research team at the University of Hertfordshire.

11 Audio-visual material

Audio recordings in some verbal tasks will be done for the purpose of transcribing it. While awaiting to be transcribed, audio recordings will be stored in a locked cupboard in the office of a researcher. As soon as the audio is transcribed it will be deleted.

12 What will happen to the data collected within this study?

- Consent forms and your personal data will be kept separately from raw data so it would not be possible to identify you.
- The raw data collected will be anonymized and stored in hard copies by the researcher in a locked cabinet for the duration of her PhD programme, after which time it will be securely stored in the Academic Supervisor's Prof. Lia Kvavilashvili office for at least 5 Years after the results are published in scientific journals.
- The data will be anonymised prior to storage.

Will the data be required for use in further studies?

The data will not be used in any further studies;

14 Who has reviewed this study?

This study has been reviewed by:

• The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is LMS/PGR/UH/03619

The University's regulations governing the conduct of studies involving human participants can be accessed via this link:

http://sitem.herts.ac.uk/secreg/upr/RE01.htm

Thank you for reading this.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me or my academic supervisors, in writing, by phone or by email:

Chief Investigator	Academic Supervisor	Academic Co-Supervisor
Brigita Brazauskiene	Prof. Lia Kvavilashvili	Dr. Ioanna Markostamou
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		Tel: 01707 285248
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Tel: 07419 785988		

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar University of Hertfordshire College Lane Hatfield Herts AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.