Information Sheet

ALF in MC Study: Assessing rate of forgetting using the ACE-III

Invitation

You are being invited to participate in research project which is investigating how we measure memory. Before you decide whether or not to participate, it is important for you to understand why the project is being carried out and what it will involve if you decide to participate. Please take time to read the following information carefully and feel free to contact us (details below) if you would like more information.

What is the purpose of the study?

We want to learn more about the early symptoms experienced by people who attend Memory Clinics and about the value of different assessment tools that are used in this setting. This is because we are interested in finding out how well the tools are able to monitor changes in memory over time. We hope that we might use this information to suggest ways in which to improve these tools. The first part of the study allowed Dr Smith to achieve a Diploma in Clinical Psychology as part of her academic studies. The funders have agreed to an extension to allow completion of the original recruitment target, where Dr Craig Newman has now taken on the role of Chief Investigator.

Why have I been invited to participate?

You have been asked to take part because we are recruiting participants from the Memory Clinics in Devon. You may have accessed the memory service as a patient yourself or possibly accompanied a spouse, a relative or someone who you care for. We are also recruiting healthy older people from local community sites, such as Memory Cafes.

Do I have to take part?

No, participation is voluntary. We would like you to consent to participate in this study as we believe that you can make an important contribution to the project. However if you decide not to participate, we will entirely respect your decision.

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed if it has not been anonymised. Should you decline to participate or later withdraw your consent from the study, this will have no impact on your current or future care.

What will happen to me if I take part?

A member of our research team will arrange to meet with you for either one or two assessment sessions either at the clinic where you received this information sheet, or at an alternate location that is convenient for you. Alternate locations include the Clinical

Psychology Department of Royal Devon and Exeter Hospital, the Research Innovation Learning and Development centre in Exeter or the Haytor Unit of Torbay hospital. We anticipate that the main meeting will last up to 2 hours and we have built in a comfort break during this time. You may also be required to attend a half hour “pre-assessment” session prior to this.

During the session, you will be invited to complete a series of activities presented to you by a researcher. Some of the activities will involve answering questions while some will be paper and pencil tasks.

All tasks will be fully explained to you, with time to practice allowed when needed. We appreciate that some people may be anxious about their memory so it may be daunting to complete tasks that are designed to test this directly. We will do our best to be sensitive to this**.**

Seven days after the assessment session, the researcher will then contact you by telephone for a brief follow-up about your experience of the research session

During this phone call, you will be supported to complete a brief booklet which we will supply. We anticipate that this will take 20 minutes. Once this has been completed, we ask that this is returned to us in the post using a pre-paid and addressed envelope provided.

You may decide to finish the study at this point but we will invite people to complete this process 12 months later because we want to investigate how people’s memory changes over time. If you express an interest in taking part in the second stage of the study, we will ask for your consent to contact your GP in 12 months time, to check that it is still appropriate for you to be contacted about the study.

Is this a medical assessment?

This is not a medical assessment. Participation in this study involves completing some standardised activities to assess memory and other thinking skills but scores from these tests would not be a sufficient basis for clinical decisions or any diagnosis. We will not be able to provide feedback of individual scores to participants.

If you have any concerns about your health, including your memory, we encourage you to discuss with an appropriate healthcare professional, such as, your GP. We will seek to inform your GP that you are participating in this research at the beginning of the study.

What are the possible benefits of taking part?

Whilst there may be no personal benefits to your participation in this study, the information you provide will help us understand the memory problems people experience and contribute to improvements in monitoring how people’s memory symptoms change over time.

The project was originally initiated as a student project, which did not attract sufficient funding to reimburse participants for travel expenses. We are not able to offer travel

costs when taking part, although home visits are possible to complete the study. We are grateful to people who volunteer their time to the project and appreciate their contribution to this work.

What about confidentiality?

Any information you provide will be treated in the strictest confidence. All information will be collected, processed, stored and destroyed according to the requirements of the Data Protection Act (1998).

Our researchers will collect and record any information you give using a unique Participant ID Number. It will not be possible for other people to identify you from the answers you have given; all data material will be presented anonymously in final reports.

In line with Plymouth University regulations for doctoral student research, anonymised data will be kept securely for a period of ten years after the completion of a research project.

What should I do if I want to take part?

When you received this information sheet, you provided consent to be contacted by telephone to discuss the possibility of participating in the study. One of our researchers will telephone you in the next 7 working days to find out whether you would like to take part. In addition, they will ask a number of preliminary questions to check that you meet our requirements for the study. These questions will relate to your health. Some health issues make it difficult to assess memory and so may indicate that it is not appropriate for you to participate in this particular project. We apologise in advance if this causes inconvenience or disappoints you.

What will happen to the results of the research study?

Initial results of this research have been written up as part of Dr Alicia Smith's thesis for her Doctorate in Clinical Psychology at Plymouth University, although further reports and publications will be written up on completion of recruitment and at the end of the study. We hope to publish this work in medical journals and present it at scientific conferences. All data will be presented anonymously in any reports, publications or presentations of this work.

A project report summarising the results of the study will be available in the summer of 2016. If you would like a copy, please contact the study investigator by email to arrange this. We would be very pleased to provide you with this.

Who is funding the research?

Funding for this project has kindly been provided by Sir Halley Stewart Trust, a UK-based charitable organisation.

Who has reviewed the study?

Plymouth University is the study sponsor. Ethical approval has been provided by Cornwall and Plymouth NHS Research Ethics Committee and Plymouth University.

Future Research

You may be invited to provide consent to be contacted about future relevant research when you have completed all stages of this study. If you agree to be contacted in the future, only your basic contact information will be stored on a separate database. The contact details we keep will be held securely and only allow relevant researchers in the future to identify individuals eligible for their research projects. The information will only be available to researchers on request and the suitability of each project will be judged on a case by case basis, with evidence of an application to a relevant Research Ethics Committee.

Contact for Further Information

Please don't hesitate to contact us, we will be glad to provide further information or answer any questions about this study at any time:

Ben McArdle – Research assistant: benjamin.mcardle@plymouth.ac.uk
01752 315258

Dr Craig Newman – Chief Investigator: craig.newman@plymouth.ac.uk

N13, ITTC North Building,
Plymouth Science Park, Davy Road,
Plymouth, PL6 8BX

We hope and do not expect anything to occur which you will be unhappy about, but should you wish to complain about your experiences with us you can address your complaints through Devon Partnership NHS Trust Patient Advise and Liaison Service (PALS). Address: PALS Team Devon Partnership NHS Trust Wonford House Hospital Dryden Road Exeter EX2 5AF. Freephone: 0800 0730741. Email: dpn-tr.pals@nhs.net

Thank you for taking the time to read this information sheet and for considering taking part in this research.