Evaluation of Memory Assessment Services (MAS)

Participant Information (patient)

We would like to invite you to help us with this research project. We have been asked by the Department of Health to help understand how people benefit from Memory Assessment Services. We would like people with memory difficulties and the people who support them to complete a questionnaire. Depending on how your clinic works, this may be in the clinic or a researcher may visit you at home.

What do I have to do?
One of our researchers will interview you about how you feel about everyday things. Even if you have some difficulties with your memory we’d still like to talk to you. There are no right or wrong answers to the questions. We simply need to know what you think and feel. We will use your details to contact you in 6 months to ask you to fill in the questionnaire again (either in the clinic or at home).

How long will it take?
Completing the questionnaires will probably take about 30 minutes each time.

Do I have to take part?
No. Taking part is entirely up to you. There is no specific benefit from taking part. It is entirely separate from any assessment for health or social care, and will not affect these. If you decide not to take part then this will not affect the care you receive.

Can I change my mind?
Yes. You are free to withdraw at any time without giving us a reason. You can also withdraw at a later date if you want to. If you choose to withdraw, this will not affect the care you receive.

Please turn over
What will happen to the information I give?
We will use the information you provide to help improve Memory Assessment Services for people with memory difficulties. We will produce a written report for the Department of Health and publish the results in academic journals. In the future, we may use your NHS number and other personal details to help us link the information that you provide on the questionnaire with other NHS information, such as the Hospital Episode Statistics database. This linkage would be done by the NHS Information Centre for Health and Social Care and would require a separate ethical review and approval. The research team at London School of Hygiene and Tropical Medicine may also use your personal details to contact you in the future to ask if you would be willing to take part in other similar research projects.

Will my personal details be safe?
Yes. All information that you give will be kept and used strictly confidentially, in accordance with the Data Protection Act and stored at the London School of Hygiene & Tropical Medicine where Dr Sarah Smith will be the custodian of the data. Your questionnaire will be given a unique number that will also be on your consent form, so that we can link your questionnaire to you if we need to (for example, if you decided to withdraw from the study). However, your personal details (such as your name, address, date of birth and NHS number) will be kept separately from your questionnaire. Any personal details that you provide will only be available to members of the research team. Published reports and survey findings will not refer to any participants by name. A copy of the consent form will also be placed in your clinic notes and we will notify your GP that you are taking part in the study.

Who has reviewed the study?
The study has been reviewed and approved by the NRES Committee London - Queen Square (REC Reference Number: 14/LO/1146).

What if I have some more questions?
Please ask any questions you want to about the study. You can ask the nurse or doctor questions now. If you have a concern later on about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Dr Sarah Smith: phone: 0207 927 2038; email: sarah.smith@lshtm.ac.uk]. If you remain unhappy and wish to complain formally, you can contact the Patient Advice & Liaison Service (PALS). Their phone number is: 01278 432022.