

**INFORMATION SHEET FOR PARTICIPANTS**

**Comprehensive modelling of outcomes for those with memory problems**

You are being invited to take part in a research study that aims to generate new evidence to inform policy and practice so as better to meet the needs of people with memory problems and their carers.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

*Please ask a research team member if anything is not clear or if you would like more information.*

**Part One** of this sheet explains the purpose of the study and what will be asked of you if you decide to take part.

**Part Two** of this sheet gives further information on how the study will be carried out.

**Part One**

**What is the purpose of the study?**

To generate new evidence to help decision‐makers in the health and social care systems to improve the wellbeing of people with memory problems and their carers in ways that make better use of society’s resources over coming decades.

**Why have I been chosen?**

People being asked to take part in this study have had a diagnosis of memory problems. You have also accessed a local NHS Memory Assessment Service in the past.

**Do I have to take part?**

*No*. It is entirely up to you to decide if you would like to take part in the research. If you do decide to take part in the research you will be given this information sheet to keep and be asked to sign a consent form.

If you do decide to take part, you are free to withdraw *at any time without giving a reason*.

Note. If you decide not to take part in the research or if you later decide to withdraw, this will not affect the standard of care you receive.

**What will happen to me if I take part?**

You will be asked to complete a series of questionnaires on two occasions, once in the next month and again in a year’s time to allow us to understand various aspects of your life, including your health, wellbeing, relationship with others, current physical and social activities, memory and support received. Members of the research team will visit you and your family carer, in your own home at a time that is convenient to you to help in completing these. This visit will last approximately 90 minutes.

Separate interviews will also be held with a family member to offer multiple perspectives and supplement any information you provide.

You will be followed up for a maximum of 1 year.

**This completes Part One of the Information sheet. If the information in Part One interested you and you are considering participating in the study, please continue to Part Two and read the information carefully before making a final decision**

**Part Two**

**Will my taking part in this study be kept confidential?**

*Yes*. The information that is gained at interview and from questionnaires will be kept confidential. When processing and storing information, we will comply with the Data Protection Act 1998 to protect your confidentiality. During the study, your information will be labelled or ‘coded’ with a participant number, not your name. All data will be stored securely.

Only a small number of researchers will have access to your personal information (e.g. name, address) to be used for contact purposes only (e.g. to arrange visits). All personal information will be stored separately to results in a secure location.

By agreeing to take part in this research, you will be agreeing to your questionnaire information being seen by other people who check that the research has been conducted correctly. These people include the Economic and Social Research Council (the funders of the research), ethics committees and regularity authorities. Anyone who works with your information agrees to hold it in confidence.

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

**What will happen to the results of the research study?**

When we have collected all the results for this study we will analyse them and then publish and present the results. You will not be identified in any publication or presentation.

**What are the possible benefits of taking part?**

The results from the study are unlikely to be directly useful to you. However, we hope that in the future the evidence collected will be useful in developing and implementing strategies to improve the wellbeing of people with memory problems and their carers in a cost-effective way.

If you would like to receive updates on the research then please tick the appropriate box on the consent form.

**Will there be any risks or other implications of taking part in this study?**

There are no risks or health implications to you by taking part in this research. All information we obtain as part of this study will be anonymised and kept confidential.

**What if there is a problem?**

If you are unable to attend a researcher visit (for whatever reason) please inform the researcher to let them know. In most circumstances another visit can be rearranged at a time convenient for you.

If you no longer would like to take part in the research then please contact a member of the research team. All data collected from the research will be kept for analysis and publication purposes unless otherwise requested. If you do decide to withdraw consent for the use of your data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that you are harmed due to our negligence, you are encouraged to approach us through the research team. Normal legal processes are also open to you. Independent advice can be sought though Ms Isla Kate Morris, University of Sussex Research Governance Officer (Email: [i.morris@sussex.ac.uk](mailto:i.morris@sussex.ac.uk), Tel: 01273 872748).

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

**What if I would like to find out the results of the study?**

If you would like to learn more about the findings of the study, please tick the appropriate box at the bottom of the consent form. At the end of the study (mid 2017), we will post you a short summary of the results for you to keep. We will also send you regular newsletters throughout the study to keep you up to date with our findings. These will describe group findings and will not include any individual information.

**Who is funding the research?**

The study is funded by the Economic & Social Research Council.

**Who has reviewed the research?**

The study protocol was reviewed and approved by the Social Care Research Ethics Committee.

**Contacts for further information**

If you require any further information about this study then please do not hesitate to contact Dr Nicolas Farina (Research Fellow) on 01273 678995. Alternatively, independent advice can be sought though the NHS Patient Advice and Liaison Service (PALS) (Tel: 01903 843022, Email: pals@sussexpartnerships.nhs.uk).

**Thank you for reading this information sheet.**