

**PERSONAL CONSULTEE INFORMATION SHEET**

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

Your relative/friend has been 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.

This Information Sheet explains more about the study, how your relative/friend will be involved, and what we would like you to do as a personal consultee.

Before you decide if you would like to act as a personal consultee, 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 your relative/friend if they decide to take part.

**Part Two** of this sheet explains the role of the personal consultee and what will be asked of you if you decide to take this role.

**Part Three** 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 was my relative/friend invited to take part?**

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

**Does my relative/friend have to take part?**

*No*. It is entirely up to your relative/friend to decide if they would like to take part in the research. If they do decide to take part in the research they will be given an information sheet to keep and be asked to sign a consent form.

If your relative/friend does decide to take part, they are free to withdraw *at any time without giving a reason*.

Note. If your relative/friend does decide not to take part in the research or if your relative/friend later decides to withdraw, this will not affect the standard of care they receive.

**What would be involved if my relative/friend takes take part?**

Your relative/friend 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 their life, including their health, wellbeing, relationship with others, current physical and social activities, memory and support received. Members of the research team will visit yourself and your relative/friend, in their home at a time that is convenient to them. This visit will last approximately 90 minutes.

Separate interviews will also be held with a carer to offer multiple perspectives and supplement any information your relative/friend provides.

Your relative/friend will be followed up for a maximum of 1 year.

**This completes Part One of the Information sheet.**

**Part Two (The Role of the Consultee)**

Before giving your opinion as to whether you would be happy to take on the role of consultee, it is important that you understand what the role entails, and what we might ask you to do.

We are intending to recruit participants to this research study who may not have the capacity to consent to their participation. This means that they may not be able to judge for themselves whether they would like to take part or refuse. We consider that it is important for people with advanced dementia to have the chance of taking part in this research study. This study has been approved by the Social Care Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, the researchers need information from people who have known the participant for some time.

**Why have I been approached?**

As a partner, friend or relative of a (prospective) participant in the study, you will have an interest in the person’s well-being and welfare. You may have been given a Lasting Power of Attorney to make personal welfare decisions on their behalf when they can’t. You may be a deputy appointed by the Court of Protection. Researcher/s in the project may discuss with you whether you think that your friend or relative would like to take part. As you have known them for some time, you may be aware of any views they may have about taking part in such a project or whether they have made an ‘Advance Decision’.

**What will we ask you to do?**

Following a discussion about this information sheet the researcher will ask you to sign a consent form which identifies you as a personal consultee for your relative/friend.

When we first meet your relative/friend, the researcher will assess whether they believe that your relative/friend has the capacity to consent to their participation in this study. This will result in one of two outcomes:

1. The researcher believes that your relative/friend does have capacity to consent to their participation. Your relative/friend will then be asked whether they would like to take part in this research, and if they do, they will be instructed to sign a consent form.
2. The researcher does not consider that your relative/friend has the capacity to consent to their participation in this study. The researcher will then ask you for your opinion about your relative/friend’s potential involvement in the study. Specifically, the researcher will ask you whether you believe that your relative/friend would have wanted to have been involved in the study, and secondly whether you consider that your relative/friend is displaying any signs of not wanting to take part in the study. If your friend/relative does have an advanced directive, the researcher will ask you if any part of the study contravenes any part of the advance decision.

The capacity of your friend/relative will be assessed by the researcher on each occasion that they see your relative/friend. We will respect the wishes of your friend/relative if they decide you should not be the personal consultee.

**This completes Part Two of the Information sheet.**

**Part Three**

**Will my relative/friend’s 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 their confidentiality. During the study, their information will be labelled or ‘coded’ with a participant number, not their name. All data will be stored securely.

Only a small number of researchers will have access to their 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, your friend/relative will be agreeing to their 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 participants’ information agrees to hold it in confidence.

Everything your relative/friend says/reports is confidential unless they tell us something that indicates they (or someone else) are at risk of harm. We would discuss this with your relative/friend 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. Your relative/friend 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 your relative/friend. 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 your relative/friend would like to receive updates on the research then ensure the appropriate box on the consent form is ticked.

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

There are no risks or health implications to your relative/friend 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 your relative/friend 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 your relative/friend decides to withdraw consent for the use of their data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that your relative/friend is 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 my relative/friend would like to find out the results of the study?**

If your relative/friend would like to learn more about the findings of the study, please ensure that the appropriate box on the consent form is ticked. At the end of the study (mid 2017), we will post them a short summary of the results for your friend/relative to keep. We will also send your friend/relative regular newsletters throughout the study to keep them 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.**