

## The Memory Research List

### Introduction

Further research is needed in order to help us understand how to diagnose, treat, cure or prevent conditions associated with poor memory including Alzheimer's disease and similar conditions. There are a large number of different ways of helping research ranging from answering simple questionnaires, agreeing to physical examinations (e.g. having a head scans or a blood test) or taking in part in studies involving taking new drug treatments.

In order to improve research into these conditions we want to put together a list of people who we can contact to tell them about studies that might occur in the future and to offer them the opportunity to take part in them if they wish. This will greatly speed up the time and the number of people we can recruit into memory research and it will also keep you in touch with the latest research developments.

### Frequently asked questions.

#### **Can I take part even if I don't have a memory problem?**

**Yes.** We need a mix of people with varying degrees of memory problems including people without memory problems.

#### **Do I have to take part?**

**No.** It is up to you to decide whether or not to put your name forward to be placed on the memory research list. If you decide not to take part then this will not affect your future care in any way.

If you do decide to take part you will be given this information sheet to keep. You will be given as much time as you need to consider whether you wish to put your name on the list and given the opportunity to answer any questions you may have. If you are happy you will be asked to sign two informed consent forms. One copy will be kept for our files and the other copy for yourself.

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

We will take a note of your name, date of birth and your NHS number for inclusion on a list. No other information is needed. With this information we will be able to access your medical notes and when a study starts we will check your details to see if you would be suitable to take part in the study. If you are suitable we will contact you by phone or letter with more information about the study. You will then have as much time as you like to decide whether or not to take part in the study. If you decide not to take part in the study this will not affect your future care in any way.

#### **How many studies and how much time is involved?**

It is entirely up to you. Each study will vary with regard to how much time is required; it is up to you to decide how much time you want to give.



### **What are the costs? Will I be paid for taking part in these studies?**

We will ensure that there is no cost to you for taking part in any of the studies. Depending on the study we will either see you at your home or if you need to attend the research centre we will arrange and pay for transport or for any petrol or other transport costs. You will not get paid for allowing your name to go on the memory research list or for taking part in any of the research studies.

### **Will my taking part in the memory research list and my medical records be kept confidential?**

**Yes.** If you take part, only qualified members of Southern Health NHS Foundation Trust (i.e. employees that are part of the appropriate research study team and their administrative support staff) will have access to the memory research list and your medical records. By signing the consent form, you are giving permission for this to happen. However, unless the law requires disclosure, the memory research list and all of your medical records will be kept confidential, and your name will not be given to anyone outside qualified members of Southern Health NHS Foundation Trust.

### **Can I take my name off the memory research list if I change my mind in the future?**

**Yes.** If you decide you no longer want to take part then you just need to inform us and we will take your name off the list. If you do withdraw from the list, the information you have already provided will be kept confidential.

### **Who can I contact for more information?**

For more information about the memory research list please contact:

Christine Dean  
South Coast DeNDRoN  
Tom Rudd Unit, Moorgreen, Botley Road  
Southampton Hampshire SO30 3JB Tel: 023 80 475864



# The Memory Research List

Please  
Initial  
Box

	I have read this form (or someone has read it to me) and its contents were explained to me.	
	I understand that relevant sections of my medical records and data collected may be looked at by the qualified members of Southern Health NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
	The study staff have answered my questions in a way that makes sense to me.	
	I understand that my participation on the memory research list is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
	I voluntarily agree to allow study staff to use and share my health data as stated in this form. I will be given a signed copy of this form for my records. I am not giving up any of my legal rights by signing this form.	
	I agree for my name, date of birth and NHS number to be included on the memory research list	

**Patients name:**

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**Signature:**

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**Date:**

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## Person obtaining consent

- There has been an opportunity for the patient, or the patient's legally acceptable representative, and the patient's caregiver to ask questions about this research list.
- I have answered all questions that the patient, the patient's legally acceptable representative, and the patient's caregiver have asked about this research list.

**Print name:**

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**Signature:**

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**Date:**

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