

Healthy Control Information Sheet

Neurosciences Healthy Control Volunteer Research Database

Introduction

We would like to invite you to be part of the Neurosciences Healthy Control Volunteer Research Database.

The purpose of this database is to provide healthy control volunteers for research projects that aim to improve understanding of dementia and related neuro-degenerative conditions. This includes research into areas such as memory, language, thinking, and movement and also broader psychosocial areas such as quality of life, and physical and mental health. Healthy volunteers allow us to make comparisons between control participants and those known to have a neuro-degenerative condition.

Why have I been asked to take part?

You have been contacted because you have responded to an advertisement that is requesting healthy control volunteers for neuroscience research.

As a healthy volunteer you are not known to have a dementia or any other problems with your memory, language or thinking.

What will I have to do?

When specific neurosciences research studies require healthy volunteers we will contact you with an information sheet which explains the requirements for that specific research study. Although each individual study will have a slightly different procedure we expect that the majority of studies would only be asking for the completion of questionnaires and cognitive assessments (a series of tests or puzzles that assess different thinking abilities). After reading the information sheet you would let us know whether you would like to take part in the research study.

How do I sign up to be a healthy volunteer?

If you decide you would like to be registered as a healthy volunteer:

- Please complete and return the contacts registration form included with this information sheet. This information will be kept on a secure database
- If you do not wish to take part this will not affect future decisions on taking part in further studies

- We would contact you on a yearly basis to confirm your consent to still be included on the registry or
- If you wish to withdraw from the database please let us know and your name will be deleted from the registry

Who is organising the project?

The Neurosciences Healthy Control Volunteer Research Database is being organised by Dr Christopher Kipps (Consultant Neurologist) at University Hospital Southampton NHS Foundation Trust.

Will my information be kept confidential?

All personal information collected about you will be kept in strict confidence in accordance with the Data Protection Act 1998. Your personal details will be kept on a secure pass-worded database within NHS premises.

Who can I talk to about this registry?

If you have a concern about any aspect of this registry you should ask to speak to the researchers involved who will do their best to answer your questions. If you wish to make a formal complaint, please contact the Patient Support Services Team at Southampton General Hospital, telephone 02381206325.

Neurosciences registry contact information

Registry Administrator: Lesley Mackinnon 02381206132
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Registry organiser:

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