



uk biobank

Brain Health Study

Participant Information Sheet

This information sheet explains what the Brain Health Study is and what it involves. It will help you decide if you want to take part.

Please take the time to read it carefully and discuss it with friends or relatives if you wish. Taking part is entirely **your choice**.



About the Brain Health Study

The UK Biobank Brain Health Study aims to help researchers understand more about how the brain works and how it influences conditions such as dementia and Parkinson's disease.

The study will not directly benefit you, but it may help improve diagnosis and care for future generations.

By taking part, you could make a big difference to brain health research.

You can find more information about the Brain Health Study on our website: www.ukbiobank.ac.uk/brain-health-study

Why have I been invited to be in this study?

You are already one of half a million people who have given genetic, lifestyle and health information to UK Biobank. Participants are being invited to take part in the Brain Health Study if they are experiencing changes in their memory, movement, smell or sleep, or if they may have been diagnosed with dementia, mild cognitive impairment or Parkinson's disease.

We used three ways to identify eligible participants:

1. Questionnaire answers

Some UK Biobank participants have completed questionnaires, for example, at our imaging centres and have told us something that suggests that they might be eligible for the Brain Health Study.

2. Survey information

We asked some UK Biobank participants to complete a new survey to tell us if they are experiencing difficulties with memory and/or movement, or if they have been diagnosed with a brain health condition.

3. Medical records

When UK Biobank participants joined the study, they agreed that UK Biobank could access their electronic health records, which contain information about their health, prescriptions and referrals.

We used this information to identify UK Biobank participants who may have concerns about their brain health, or who have been diagnosed with a brain health condition such as dementia and/or Parkinson's disease.

We decided on these methods following discussions with experts doing similar research, our Ethics Advisory Committee and some of our participants.

You can read more about our agreement with you and how we use your data on the UK Biobank website: www.ukbiobank.ac.uk/taking-part/our-agreement-with-you



Do I have to take part in this study?

No. Taking part is **your choice**. If you decide you do not want to take part, then this will not affect your ongoing relationship with UK Biobank.

You can change your mind about taking part at any point. Just let us know. There is no need to give a reason.

What does taking part in the Brain Health Study involve?

If you choose to take part in the study, we will arrange for you to visit one of our local research centres on a day that suits you. If you think you might need support getting to the research centre, getting around the research centre or remembering your medical history, we recommend that you bring a close relative or friend with you.



A friendly member of our experienced team will guide you through every part of the visit and will be on hand to answer any questions you may have.

The research visit will last approximately 3 hours.

At the research centre we will ask you to:



Answer some questionnaires and complete some memory activities



Give a small sample of your blood (26.5ml; about 9oz)



Have an MRI scan of your brain



Complete a smell test



Complete an eyesight test



Complete a keyboard-tapping task



Wear a device home so that we can measure your activity, sleep, movement and heart rhythm for 7 days. We will send you a reminder to post the device back to us in a pre-paid postage box that we will give you.



If you are willing to, identify a relative or close friend who could complete an online questionnaire to help us understand your brain health and daily living from another point of view.

The role of a companion

We encourage you to come to the research centre with a close relative or friend, particularly if you think you might need support:

- getting to the research centre
- getting around the research centre; or
- remembering your medical history.

Your companion should be at least 18 years old.



Since the visit will take approximately 3 hours, your companion (if you bring one) may wish to bring a book, magazine or something else to keep them occupied during times that you are doing study activities that do not require them (for example, while you are having a brain MRI scan).

How will I get to the research centre?

We want to make it as easy as possible for you to take part in the Brain Health Study.

We can:

- arrange complimentary door-to-door transport for both you and your companion
- reimburse your travel costs and provide directions and travel advice if you prefer to use your own transport.

See www.ukbiobank.ac.uk/brain-health-study for further information.

We will discuss this with you when you book your appointment.



Is there anything that would mean I am unable to take part?

MRI scans use strong magnets, so you may not be able to have a scan if you:

- have an electrical implant (for example, a heart pacemaker or a shunt) in your body; or
- have had a brain implant like a clip or a coil.

Some medical problems may make it difficult for you to have a scan (for example, being unable to lie still on a flat surface for half an hour).

If you would like to take part in the study but are not sure if you would be able to have a brain scan, please telephone us on 0800 0 276 276 so that we can check this for you.

For more details, please see the MRI Information Sheet.

Will I find out the results from my visit?

No. As is standard practice for UK Biobank, the tests and scans are collected for research purposes only and are not reviewed by a doctor.

We are therefore unable to provide you with any results.

- The visit is **not a health check**.
- We **cannot diagnose any medical conditions**.

However, we will contact you and your GP if the radiographer doing your brain scan sees something abnormal and unexpected that may be medically important.

In another UK Biobank study, we found abnormal appearances in 1 out of 100 brain scans. For half of these people, the abnormality turned out to be nothing to worry about.

Joining the study will not affect the care you receive from your doctor. More information about our approach to feedback can be found on our website: www.ukbiobank.ac.uk/taking-part/our-agreement-with-you

What will happen to my information from the Brain Health Study?

- We made an important commitment to you when you joined the study. We promised to protect your confidentiality while making your data available for ground-breaking health research for the benefit of current and future generations.
- We share UK Biobank data only with approved researchers from academic, charity, government and commercial organisations across the world for health-related research that is in the public interest.
- Information that identifies participants – for example, your name, address and NHS number – is never shared with researchers.
- The data collected in this study will be combined with the other information and samples that you have already provided to UK Biobank. It will be stored securely by UK Biobank for many years.
- Your personal details, e.g. your name, address, phone number and NHS number, are stored separately from any research data.

More information is available on our website at:

www.ukbiobank.ac.uk/taking-part/our-agreement-with-you/participant-privacy-notice. This explains how we protect your data.

You can read stories about how healthcare is being changed by discoveries made with your data on our website:

www.ukbiobank.ac.uk/research-stories

What are the possible benefits of taking part?

The study will not benefit you directly. By taking part, you will help scientists better understand the brain, and this could lead to advances in the treatment and prevention of brain health conditions like dementia and Parkinson's disease for future generations.

What are the possible risks of taking part?

The scan and other research activities are safe, painless, and relatively quick and comfortable. Participating in this study should not cause you any harm.

You may feel some discomfort when you have blood taken. There is the possibility of bruising and/or fainting, although our staff are trained to reduce the risk of this.

The MRI scan uses powerful magnets, and we take great care to prevent magnetic objects from entering the MRI room.



When you book your appointment and when you arrive at the research centre, we will ask you some questions about your medical history to check that it is safe for you to have a brain scan. We will also make sure that you are made as comfortable as possible during the scan. Please see the MRI Information Sheet for more details.

You may find the research centre visit tiring, but you can take breaks when you need them. Our staff will be on hand to support you and help make your research centre visit as enjoyable as possible.

What should I do if I want to be in this study?



Step 1: Read this sheet. Make sure that you read this information sheet carefully (and talk to friends or relatives if needed). You can also find further information about the study on the study website: www.ukbiobank.ac.uk/brain-health-study



Step 2: Call us. Please let us know if you are interested in taking part by phoning us free of charge on 0800 0 276 276 (Monday to Friday 9am to 5pm). You can also request a phone call from us by visiting the study website.



Step 3: Ask us questions. During this call, you can ask us any questions you might have. We will also ask you questions about your medical history to check that you can have a brain scan.



Step 4: We will book you in. If it is ok for you to have a brain scan, we will arrange an appointment for you (and your companion, if you are bringing one) at your nearest research centre. You will be able to select a date and time that suits you both. Appointments are generally available from 9am to 4pm, 7 days a week.



Step 5: You will get a confirmation. We will send you a letter confirming your appointment and providing you with directions to the research centre.



Step 6: You will get a reminder. If you have provided us with an email address and/or phone number, we will also remind you about your appointment before your visit.

Who has reviewed this study?

All research conducted by UK Biobank is looked at by an independent group of people, called a Research Ethics Committee, to protect the safety, dignity, and wellbeing of research participants. This study has been reviewed by the North West – Haydock Research Ethics Committee, 21/NW/0157.

Who do I contact if I have any questions?

If this information sheet does not answer your questions, please:

- visit our website at www.ukbiobank.ac.uk/brain-health-study
- phone us free of charge on 0800 0 276 276 (Monday to Friday 9am to 5pm); or
- email us at ukbiobank@ukbiobank.ac.uk

If you would like to contact the person in charge, please:

- send a letter to Professor Sir Rory Collins, Principal Investigator, UK Biobank, 1-2 Spectrum Way, Adswold, Stockport, Cheshire, SK3 0SA; or
- send an email to ukbiobank@ukbiobank.ac.uk

If you would like to make a complaint to a nominated person independent of the research team, please send an email to Nicola Perrin, MBE (Chair of the UK Biobank Ethics Advisory Committee) at N.Perrin@amrc.org.uk

We will reply to your letter or email promptly in writing, unless you ask us to phone you.

Further resources and support

If you would like dementia advice or support, please contact your GP or the Alzheimer's Society Dementia Support Line on 0333 150 3456.

Thank you for supporting UK Biobank.

UK Biobank Limited (company no. 4978912) is a registered charity in England & Wales (1101332) and in Scotland (SC039230)

uk **biobank**