



uk biobank

Brain Health Study

Participant Information Sheet

- This information sheet explains what the Brain Health Study is, why we are doing it, and why we would like your help. It will help you decide if you want to take part.
- Please take the time to read this leaflet carefully and discuss it with others if you wish.
- If possible, we would like someone who knows you well to take part in the Brain Health Study with you (called a Study Partner), although this is optional.
- You can find more information about the Brain Health Study on our website at: <https://www.ukbiobank.ac.uk/brain-health-study>
- Taking part is entirely voluntary. It will not affect your ongoing relationship with UK Biobank if you decide not to take part.
- Please keep this information leaflet so you can refer to it later.

About the UK Biobank Brain Health Study

The UK Biobank Brain Health Study aims to help scientists better understand a wide range of brain-related diseases such as dementia and Parkinson's disease. The study will not directly benefit you, but it will lead to better ways to diagnose and treat these diseases for future generations. By taking part, you could make a big difference to brain health research.

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.

You have been invited to take part in this Brain Health Study because you completed our Brain Health survey, and your answers show that you are eligible to take part.

Do I have to be in this study?

No, you can choose if you want to be in this study or not. Your decision 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 possible, we would like someone who knows you well to come with you to the research centre to support you during your visit and to provide additional data.

A friendly member of our team will guide you through every step of the visit.

At the research centre we will ask you to:

- do some memory tests and questionnaires so we can check your cognitive function.
- give a small blood sample (25.5 ml; about 0.9 oz) for us to look for markers in the blood that might indicate different diseases.
- have an MRI scan of your brain to produce pictures for us to look at its structure and function.
- do a test to see how well your brain senses smell.
- wear a device home with you (that we will give to you at the visit) so that we can measure your activity, movement and heart rhythm for 7 days.
- take a small sleep mat home (around 2 feet long and 7 inches wide) that will fit under your mattress and measure your sleep patterns for 14 days.

The visit will last approximately 3 hours.

What is a Study Partner and what would they do?

A Study Partner is someone you are close to and who knows you well. They could be a family member such as your partner/spouse, your child or another relative or close friend. They should be at least 18 years old.



We would like this person to come to the research centre visit with you. At the visit, your Study Partner will be able to help you if you need it. With your permission, we will also ask them some research questions about your daily living and they can help answer questions about your medical history so that we can check that you are able to have the imaging scan.

Bringing along a Study Partner is optional, but we encourage you to have someone with you during the visit, if you can.

How will I get to the research centre?

We want to make it as easy as possible for you to take part. If it would be helpful, we can arrange door-to-door transport for both you and your Study Partner. We will ask you about this when we talk to you on the telephone about your appointment.



If you prefer to use your own transport, we will provide you with directions and travel advice and will pay your travel costs. You can read about claiming travel expenses on the Brain Health Study webpage FAQs: <https://www.ukbiobank.ac.uk/brain-health-study>.

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 be in the study but are not sure if you would be able to have a brain scan, please telephone us (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, you will not receive the results of the tests or a diagnosis. This is because the information we are collecting is just for research and is not checked by a doctor.

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.

Abnormalities might turn out to be something harmless like a cyst or a technical issue with the scan. It could also be related to a condition that you and your GP already know about. However, other abnormalities might affect how your body functions, your quality of life, or your lifespan.

In case it is something more serious, we will ask for your permission to tell you and your GP if we notice something in your scan.

Joining the study will not affect the care you receive from your doctor.

What will happen to my information?

The information we collect will be shared with approved researchers around the world for health-related research in the public interest. When we share your information, we remove your name and other personal information from your data and use codes instead. We do not include any details that will identify you in any information or samples we give to 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. name, address, phone number, NHS number) are stored separately from any research data.



The way in which UK Biobank collects, shares, and uses your information is explained on our website at: www.ukbiobank.ac.uk/explore-your-participation/basis-of-your-participation. This includes an explanation of how we protect your data.

All researchers need to apply and get approval to use any UK Biobank data, and they must use it for health-related research that is in the public interest. This is the same for researchers from universities, charities, government agencies or commercial companies, and for researchers based in the UK or abroad.

Researchers must make public the results of all research using UK Biobank data so that everyone can benefit from it. You can find out about research that is being conducted using UK Biobank data on our website at: <https://www.ukbiobank.ac.uk/learn-more-about-uk-biobank/our-impact>.

What are the possible BENEFITS of taking part?

The study will not benefit you directly. By taking part, you will help scientists better understand brain-related diseases and find new ways to prevent and treat these diseases for future generations.

What are the possible RISKS of taking part?

The scan and other measures 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?

First, 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 our website at: <https://www.ukbiobank.ac.uk/brain-health-study>.

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 our website at <https://www.ukbiobank.ac.uk/brain-health-study>.

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.

Once we have completed these initial checks and confirmed that you are able to take part, we will arrange an appointment for you (and your Study Partner) at your nearest research centre. You will be able to select a date and time that suits you both. Appointments are generally available from 10am to 1pm, Monday to Sunday, and will last for approximately three hours.

We will send you a letter confirming your appointment and providing you with directions to the research centre.

If you have provided us with an email address and/or phone number, we will also remind you about your appointment a few days 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 well-being 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 <https://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.

Thank you for your continued support of UK Biobank

By being part of UK Biobank, you are helping to drive scientific discoveries that are improving human health.

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