



uk biobank

Brain Health Study

Information Sheet for Study Partners

- Your relative/friend is taking part in the UK Biobank Brain Health Study.
- They have nominated you, as someone who knows them well, to join them in the study as their Study Partner.
- We would like you to complete an online questionnaire about your relative/friend's brain health and daily living. This information will be used along with information your friend/relative has provided for the Brain Health Study to help scientists to better understand brain health conditions. **You can complete the questionnaire at the research centre or from the comfort of your own home.**
- 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 information sheet carefully and discuss it with others if you wish.
- You can find out more about the Brain Health Study on the study website at www.ukbiobank.ac.uk/brain-health-study.
- **Taking part is entirely voluntary** and will not affect your relative/friend's ongoing relationship with UK Biobank.
- Please keep this information sheet to remind you about the UK Biobank Brain Health Study.

What is UK Biobank?

UK Biobank is the world's most comprehensive dataset of biological, health and lifestyle information. Half a million volunteers, aged between 40 and 69 years, were recruited between 2006 and 2010. Your friend/relative is one of our participants. At recruitment, physical measures were taken together with information about lifestyle, medical history, and samples of blood, urine and saliva, which are stored for future analysis.

After personal identifying information is removed from the data, scientists from across the world can apply to use it for research that will benefit the public, such as understanding the causes of disease.

Researchers all over the world are using UK Biobank data to make scientific breakthroughs and advance healthcare.

With their consent, our participants continue to provide detailed information about their lifestyle via online questionnaires, as well as data from their health records and related information, to provide a deeper understanding of how diseases develop.

Some of our participants have also visited one of our research centres and had body scans and provided blood samples. Sometimes we also ask them to wear devices such as activity monitors.

About the UK Biobank Brain Health Study

The UK Biobank Brain Health Study aims to collect detailed information about the brain health of UK Biobank participants. We hope that this will help researchers understand more about how the brain works and how its health influences conditions such as dementia and Parkinson's disease. This may help improve diagnosis and care for future generations.

Existing UK Biobank participants who take part in the study will visit one of our research centres. During this visit, they will be asked to:

- do some questionnaires and memory activities
- give a small sample of blood (26.5ml; about 0.9oz)
- have an MRI scan of their brain
- complete a smell test
- complete an eyesight test
- complete a keyboard tapping task
- wear a device home so that we can measure their heart rate, activity and sleep for 7 days
- identify a relative or close friend who could complete an online questionnaire to help us understand the participant's brain health and daily living from another point of view.

The visit will last approximately 3 hours.

The data collected in this study will be combined with other information and samples that our participants have already provided to UK Biobank. By taking part, your relative/friend could make a big difference to brain health research.

What is a Study Partner and how is this different from accompanying my relative/friend to the research centre?

Regardless of whether a participant needs support or assistance to attend their research centre visit, they will be asked whether they are happy for a close relative/friend who is over the age of 18 years old to answer some questions about their daily living and functioning.

By answering this questionnaire as a Study Partner, this means you would be contributing to the information used by scientists to better understand brain health conditions.

If you are attending the research centre with your friend/relative and they have given consent for you to answer this questionnaire about them, you can complete this while they complete their tasks.

If your relative/friend is attending the research centre visit on their own, they will be provided with written instructions to pass on to you about how you can complete this questionnaire from the comfort of your own home.

Do I have to be a Study Partner in the Brain Health Study?

No. You can choose whether to take part as a Study Partner in the UK Biobank Brain Health Study. Your friend/relative can still contribute to the study without a Study Partner if they wish. We understand that you may not have time or feel able to help.

You can change your mind about being a Study Partner at any point. Just let us know by calling us on 0800 0 276 276 or by emailing us at ukbiobank@ukbiobank.ac.uk

Are there any benefits of taking part as a Study Partner?

Whilst there are no immediate benefits for Study Partners taking part in the study, it is hoped that this work will enable researchers to:

- define and identify different types of brain health conditions
- better understand the causes of these different types of brain conditions
- develop new treatments specific to each type of disease.

You can read stories about how healthcare is being changed by discoveries made with your data on our website at www.ukbiobank.ac.uk/research-stories

What happens to the information I provide to UK Biobank?

Any information you give us about the participant's daily life and functioning will be combined with the other information and samples that they have already provided to UK Biobank. It will be stored securely by UK Biobank for many years.

- 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 and Study Partners – for example, their name, address and NHS number – is never shared with researchers.
- Your personal details, e.g. your name, address and phone number will be stored separately from any research data. We will only use this data for administrative purposes and to contact you about your participation in UK Biobank.

More information is available on our website at

www.ukbiobank.ac.uk/brain-health-study-privacy-notice.

A paper copy of this notice is available by calling us on 0800 0 276 276, or from our Brain Health Study Research Centre.

What should I do if I would like to take part?

If you have read this information sheet and would like to take part, please visit our website using the QR code or website address provided to you with this information sheet and register to take part. You will be asked to provide some basic personal details and complete a consent form before completing the questionnaire.

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 participants' interests. This study has been approved by the North West – Haydock Research Ethics Committee, ref. 21/NW/0157.

What should I do 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.

Signposting to support

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

Thank you for supporting UK Biobank.

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