Dementia Research
Powered By People

GlobalMinds
Dementia

Research to shape the future of dementia treatment.

Participant Information Sheet

Funded by
Wellcome

We are inviting you to take part in GlobalMinds, a research programme for dementia.

Contents

1. A bit about us

What is GlobalMinds?

GlobalMinds is a research programme aiming to improve the lives of people diagnosed with dementia, mild cognitive impairment (MCI), and subjective cognitive impairment [also known as subjective memory disorder] (SCI). We are trying to understand the links between brain conditions and human biology, and better understand what defines these illnesses.

To do this, we are inviting of people affected by these conditions to help us create a digital dataset of health information and DNA. Researchers will use this dataset – one of the largest of its kind in the world – to better understand these conditions and help to answer questions like:

- How do our genes and other aspects of our biology affect our risk of developing dementia?
- How can we target the underlying causes of these conditions instead of just acting on the symptoms?
- Can we predict and reduce this risk for people in the future?
- How markers and cells in blood may be associated with features of dementia.

GlobalMinds is run by a research company called Akrivia Health (who specialise in mental health and the dementias), in partnership with Cardiff University and the NHS. It is funded by the Wellcome Trust and Johnson & Johnson*.

*Janssen Pharmaceutica NV

2. What joining GlobalMinds involves

Why have I been invited to take part?

We're inviting you to take part because you're aged 18 or over, live in one of our research regions and have a diagnosed cognitive disorder, such as:

- Dementia (of any kind)
- Mild Cognitive Impairment
- Subjective Cognitive Impairment/ memory disorder.

Do I have to take part?

It is entirely up to you if you would like to take part in this study. Whether you take part in this study or not your treatment and care will not be affected in any way. If you change your mind you can withdraw at any time, and you don't have to give a reason.

For more information, see the section: What if I change my mind?

Will it improve my health?

GlobalMinds will make discoveries by searching for patterns in data from large numbers of participants. It will not make discoveries about individuals, so you won't learn anything new about your own condition or overall health by taking part. Taking part in GlobalMinds will not affect your current healthcare in any way.

What will I be asked to do?

Step 1: Speaking to your healthcare research team

You may be contacted by a member of the research team at a local health clinic/hospital about the study. They will briefly explain GlobalMinds, send out information about the study, answer any questions you may have at the time, and invite you to attend a study visit.

Step 2: Study visit

At the visit you will be asked to complete a brief screening assessment to determine if you are eligible. If you are eligible and decide to take part, you will sign a consent form stating that you agree to take part in the study. You will be given a copy of your completed consent form to keep for your records.

We will ask you to complete, with the support of the researcher, an online assessment (taking up to 2 hours on a platform known as Trialdeck. It may be referred to as 'the hub') which includes general questions about you, your diagnosis, symptoms, and any treatment. If you wish to you may nominate a study partner, a friend, family member, or carer, who can support you during the visit and answering any questions. This is completely up to you.

We will also ask you to provide blood samples (maximum 44ml of blood; just under 3 tablespoons). This may be done at the same time as the assessment or at a different time. The researcher will discuss this with you to find out what would be best.

On rare occasions, if there are problems with your original samples, for example delivery delays, then it may be necessary to ask you to provide additional samples at another time. If you agree, the researcher will contact you to arrange this.

You may also be asked to complete some additional questionnaires in your own time. They take approximately 30 minutes to complete and are entirely optional.

How long will the research take?

Learning about the research and completing the consent form will take approximately 15 – 30 minutes.

There is an online questionnaire which could take up to 2 hours.

Donating a blood sample takes 10–15 minutes.

Completing the optional additional questionnaires will take 30 minutes.

Would I be paid to take part?

Participants who complete their visit will receive a £50 love2shop voucher as a thank you for taking part. If you travel far to attend your visit, reasonable travel expenses will also be paid to you. To allow us to process your travel expenses, your details will be provided to Akrivia Health's finance department.

3. How your data and samples will power research

What data is collected and why?

Akrivia Health collects data including:

Categories of data	How we use it
Your name and contact details	We use this data to communicate with you.
Direct identifiers that relate to you (NHS number, study ID).	We use this data to identify you, and data collected to you, to link study data together, and link with other datasets.
Information about your health like diagnosis, questionnaire answers.	We use this data to ensure you are eligible to take part in the study, and to answer research questions.
Data that we obtain by analysing blood or saliva samples you provide.	We use this data to answer research questions.
Demographic information like your age, ethnicity, and sex.	We use this data to answer research questions, and to ensure that the study data comes from a number of participants that properly represents the population.
Technical identifiers	Data collection will predominantly be through an online platform. We will store a username and password

How will my information and samples be used?

Blood contains genetic information (DNA) and other biological markers that can reveal clues about our health. The blood sample will be used for a series of research purposes, including creation of cell lines, stem cells (induced pluripotent stem cells or iPS cells, which are cells with the ability to divide for indefinite periods and to give rise to specialized cells), and the study of biological characteristics, DNA, RNA (gene expression), proteins and other biological markers. This will allow us to look for genes and other factors which make some people more likely than others to become ill. We hope that our study will improve understanding of these conditions and help find better treatments in the future. Blood samples will be stored securely and anonymously at a lab which has a license for storing blood and saliva samples.

By extracting and analysing material from the donated samples and combining this with the health information you provide, GlobalMinds will help researchers to understand the links between genes, symptoms and dementia. All your data will be anonymised – meaning that researchers will not be able to identify you from this data. If you consent to this, we will link the data we get from your blood sample with anonymised copies of your health records.

Your information will be used for research

Researchers who wish to use the GlobalMinds library in their research will have to apply to access the information they need.

Our Data Access Committee will review each application and decide whether permission can be granted to that researcher. If access is granted, GlobalMinds will anonymise and prepare the data required, and researchers will have a secure online route to study it. There will be controls to prevent them from saving or sending it elsewhere. If they need to do this as part of their study, they will have to apply for permission.

The Data Access Committee will check to make sure researchers are using the information in the way that was agreed.

4. Protecting your data and identity

How will you protect my data, confidentiality and identity?

Personal data means data that relates to you, and this includes information that you give when taking part in the study.Personal data will be stored and handled securely, in line with data protection laws, including the UK General Data Protection Regulation (UK GDPR) and the relevant security standards.

You can find further information in the information sheet appendix or our full privacy notice. If you have any further questions about privacy or confidentiality you can contact our data protection officer by email at **DPO@akriviahealth.com**.

Is taking part private?

You don't have to tell your GP, clinical care team, or anyone else that you are taking part in GlobalMinds if you don't want to.

We will never publish your name or tell your care team that you are part of GlobalMinds. But if you enrol in person at your clinic/hospital, they will know.

We will contact the NHS for access to your health records, but those involved in your care won't be notified about this.

What happens when the study is finished?

GlobalMinds is a long-term study that will allow us to learn a lot about the causes and triggers of mental/neurological illness and/or cognitive problems.

The GlobalMinds library will power research discoveries. Some of these discoveries might be tiny steps, some may be bigger breakthroughs. All research progress will bring us closer to improving the lives of people living with dementia.

The researchers who make these discoveries will publish their findings in scientific literature and present them at conferences. We will share this news via Akrivia's website and social media.

You will not receive specific results or feedback from your participation in the GlobalMinds study.

Future opportunities

We will ask for your permission to contact you in the future about related research that we think you could be a part of.

You can say yes or no.

What if I have a complaint?

We have tried to ensure that taking part GlobalMinds is as seamless as possible for our participants, however we know that things may not always go to plan.
If you have any feedback or would like to make a complaint, there are a number of ways in which you can do this:

- You can contact the PALS service at the health clinic/hospital where you attend your study visit. Contact details: [ADD]
- You can submit a complaint on the online platform where the questionnaires will be filled.
- You can submit a form via the website at: [LINK]
- You can contact the central GlobalMinds team directly at: **globalminds@akriviahealth.com**

5. Benefits and risks of joining GlobalMinds

What are the risks of taking part?

The study will not affect any treatment or medical advice you receive. There is very little risk of physical injury in taking part. Having a blood sample taken may cause discomfort and minor bruising around the area. Some people become lightheaded or faint, but this is rare.

Some people may find it difficult to answer questions about their mental health condition in the questionnaire(s). You'll be able to take as many breaks as you need. The researcher and central GlobalMinds team are also here to help you through the process.

We are taking a lot of security precautions with your personal data, including being certified according to standards set by the National Cybersecurity Centre and the NHS.

However, the risk can never be zero. There is a small risk that, if there was a security breach, someone could see or use the data we have about you.

What are the benefits of taking part?

Being part of a research programme like GlobalMinds is a generous act to help others. By taking part, you will help researchers to make breakthroughs in the understanding of mental health conditions and dementia. This could lead to improvements in prediction, prevention, diagnosis and treatment of these conditions in the future.

You will receive a voucher for enrolling (see the section: Would I be paid to take part?). You will not benefit financially in any other way, even if discoveries made from GlobalMinds lead to commercial gain for researchers.

What if I change my mind?

You can withdraw from GlobalMinds at any time, without giving a reason and with no impact on your current healthcare. We will ask you if it's OK for GlobalMinds to continue storing and using the data and samples that you provided.

If you say yes, we will keep your data and samples for future research, but we will not contact you again with any follow-up questionnaires or to invite you to future research.

If you say no, we will destroy the data and samples that we hold about you and these will not be used in future research. We will keep your name and study ID so we can make sure we don't contact you again.

We would not be able to remove your data from anonymous datasets that have been prepared for research from the GlobalMinds library.

Because, in these cases, it is not possible to identify data that relates to you.

7. Partners and funders

How are you funded?

Akrivia Health is a health research company. It is the main sponsor of GlobalMinds, responsible for running the programme and securely looking after the programme's dataset. Akrivia was set up by an NHS doctor and an Oxford University researcher who believe data research will speed up discoveries about mental health and the dementias.

GlobalMinds also receives funding from the leading global charity the Welcome Trust, which funds projects towards their vision, of 'a healthier future for everyone'. And from our industry partner Johnson & Johnson*, who have been involved in mental health research since the 1950s.

While these funders can access the GlobalMinds dataset to power research, they do not have access to data that can identify any individuals taking part in GlobalMinds.

Who are you partnered with?

NHS Mental Health Trusts across the UK are helping GlobalMinds to reach people who are eligible to take part in the programme. Researchers at our partnered Trusts can also apply to access GlobalMinds to power mental health research. Visit our website for a live list of partnered Trusts.

Cardiff University and the National Centre of Mental Health are providing expert advice to help us make GlobalMinds the best it can be.

Please visit our website to find more information about our funders and partners.

Thank you for taking the time to consider joining GlobalMinds – dementia research powered by people.

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