



# Research to improve the lives of people living with mental health conditions.

Participant Information Sheet





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# We are inviting you to take part in GlobalMinds, a research programme for mental health.

### Taking part involves:

- Reading some information about GlobalMinds
- Reading and signing a consent form
- Filling in a questionnaire
- Giving a sample of your blood or saliva.

Before you decide if you would like to take part, it is important that you understand what the programme is and what it involves.

### We provide that information here, and aim to answer questions you might have, including:

- What is GlobalMinds?
- What would I have to do?
- Will it improve my health?
- Is it confidential?
- Will my data be safe?

Please take time to read all the information. If you have any questions, please email us at

[globalminds@akriviahealth.com](mailto:globalminds@akriviahealth.com) or call +44 (0)330 332 4878.

# 1. A bit about us

## What is GlobalMinds?

GlobalMinds is a research programme aiming to improve the lives of people diagnosed with depression, schizophrenia, bipolar and related conditions.

To do this, we are inviting tens of thousands of people affected by these conditions to help us create a digital dataset of health information and biological information, including genetics.

Researchers will use this large dataset – one of the largest of its kind in the world – to better understand mental health conditions and help to answer questions like:

- How do our genes and other aspects of our biology affect our risk of developing mental health conditions?
- Can we predict and reduce this risk for people in the future?
- How can we improve the way these conditions are detected and diagnosed?
- Why do some people become more ill from these conditions than others?
- How can we improve on current treatments to reduce side effects?
- How can we target the underlying causes of these conditions with new treatments, instead of just acting on the symptoms?

GlobalMinds is run by a research company called Akrivia Health (who specialise in mental health), in collaboration with Cardiff University and NHS Trusts.

It is funded by the Wellcome Trust and Johnson & Johnson\*.

\*Janssen Pharmaceutica NV

# 2. Taking part and your health

## Why have I been invited to take part?

We're inviting you to take part because you're aged 18 or over, you live in one of our research regions and you have a diagnosis for a mental health condition such as:

- major/clinical depression
- schizophrenia and/or psychosis
- bipolar and/or mania
- or a related condition.

## Do I have to take part?

No. You are free to choose whether you want to join GlobalMinds, or not.

Your treatment and care will not be affected in any way, whatever you choose.

If you decide that you would like to take part, you can change your mind at any time without giving a reason. For more information on this, 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 tens of thousands 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.

Discoveries made from GlobalMinds will improve the understanding and treatment of mental health conditions, but advances could take many years.

Taking part in GlobalMinds will not affect your current healthcare in any way.



## 3. What joining GlobalMinds involves

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### What will I be asked to do?

Taking part involves reading information and signing a consent form, completing questionnaires and providing a sample of your saliva or blood.

#### Step 1: Check your eligibility

If you are interested in taking part, we'll ask you to fill in a short form. We will ask for your postcode, NHS number or details of the clinic you attend, and permission to access your medical record.

This is so we can check that you have a recorded diagnosis for one or more of the conditions being studied in GlobalMinds, and live in one of our research regions.

#### Step 2: Provide permission, information and a blood/saliva sample

If you are eligible to join GlobalMinds, and you choose to take part, we will ask you to:

- Read and sign a consent form to confirm that you agree to take part in GlobalMinds.
- Give permission (by signing the consent form) for us to access, link and analyse health records about you. This includes things like GP and hospital notes.

- Give permission (by signing the consent form) for health researchers to study the information you have provided.
- Complete an online questionnaire about you, your mental and physical health, symptoms and treatments (15-25 minutes).
- Give a sample of your saliva or blood (you choose which).
- [OPTIONAL] Complete more questionnaires and/or measures of cognitive function, if you wish to.
- [OPTIONAL] Opt in to be contacted in future by GlobalMinds to provide additional information about you and your condition.

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### How would I give a sample of saliva or blood?

Depending on your choice, we will ask you to provide a sample of your saliva (2ml, about half a teaspoon) or blood (44ml, about 2.5 tablespoons).

If you enrol online or in person and choose to provide a saliva sample, you'll receive a kit and full instructions within 5 working days. You can then post your saliva sample back to us for free. We will let you know we've received it within 5 working days of it reaching us.

If you enrol online and choose to provide a blood sample, you'll receive a kit within 5 working days. This will guide you through booking an appointment for a trained practitioner to visit you at home to take the blood sample.

Your sample will then be collected by a courier (at no cost to you) and we will let you know we've received it within 5 working days of it reaching us.

Please note: we cannot visit the homes of people with a history of violence, or where there are animals that may present a risk. If either of these things are the case, we will ask your permission to speak to your health professional, to try and find a safe way for you to provide a blood sample.

If you enrol in person, at a GP surgery or hospital, and choose to provide a blood sample your blood can be taken on the day, by a member of the research team.

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### Would I be paid to take part?

We will provide a thank you voucher to everyone who enrolls and completes Step 2 (see above).

- £25 voucher for taking part and providing a saliva sample.
- £50 voucher for taking part and providing a blood sample.

Or you can choose to donate the money to a charity of your choice.

If you have to travel to take part, we can pay reasonable travel expenses.

## 4. How your data and samples will power research

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### How will my information and samples be used?

Blood and saliva samples will be stored at a secure, licenced lab.

Blood and saliva contain genetic information (DNA) and other biological markers that can reveal clues about our health. 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 mental health.

If you choose to provide a blood sample, your 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.

### Your information will be used for research

Researchers who wish to use the GlobalMinds dataset 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.

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

## 5. Protecting your data and identity

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### How will you protect my data, confidentiality and identity?

Your 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 detailed information about the personal data we are collecting in this study, what it is used for and how it is stored and protected, in our full privacy notice on our website.

### Is taking part private?

You don't have to tell your GP, mental health 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, 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. If you enrol online, it will not show up in your NHS records.

### Who will look after my data?

Akrivia Health is the research company in charge of GlobalMinds.

They are responsible for securely storing your data and samples and will strictly control who has access to them.

Only the small study team directly responsible for delivery of GlobalMinds at Akrivia Health will have access to directly identifiable data, such as your name and contact details. It's important we maintain this information while GlobalMinds is ongoing, so we can re-contact you or act on requests to withdraw from the study.

We will share this information only with necessary approved suppliers who process data on our behalf, for instance, to send out the sample kits, or to the NHS to add your health records to our research library.

All personally identifiable data, like name and contact details, will be removed from any information that is accessed by approved researchers. This means they won't be able to identify who you are from your health information or samples.

You can find out more about how we'll use your information by contacting Akrivia's data protection office at [DPO@akriviahealth.com](mailto:DPO@akriviahealth.com) or in our full privacy notice on our website.

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## How long will you keep my data?

GlobalMinds is a long-term programme that will continue to inform research discoveries for many years. We will store your data for the duration of the programme, unless you ask us to destroy it (see: What if I change my mind?).

If GlobalMinds finishes, or we no longer require your sample, we ask your permission to pass the sample and data (i.e. not your name or contact details) to an approved repository, or 'biobank' to keep these samples and information. You can say yes or no.

If you say yes, the biobank will then control access to your data and samples and make them available to other researchers. You will not be contacted by these researchers.

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. You can also choose to have your samples destroyed at any time, and please contact us if you do wish to withdraw your sample.

Identifiable data held by the GlobalMinds team will be archived for 5 years after the end of the GlobalMinds study. De-identified data and retained samples will be kept indefinitely. With your permission,

we will retain contact information indefinitely for the purpose of approaching you about future research opportunities.

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## What are my rights?

You have rights over your personal data, sometimes called information rights. With this, you can:

- ask questions about your data by emailing **DPO@akriviahealth.com**
- ask us to see the data we hold about you
- ask us to correct inaccurate data
- ask us to stop using the data we hold about you
- ask us to delete the data we hold about you
- complain to the **Information Commissioner's Office (ICO)**.



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## 6. Benefits and risks of joining GlobalMinds

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### What are the risks of taking part?

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 save your progress so you can take as many breaks as you need.

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.

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### 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. 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.

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### What if I change my mind?

You can withdraw from GlobalMinds at any time, without giving a reason.

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. Collaborators 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.

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

While these funders will be able to access GlobalMinds data once it has been made anonymous, they do not have access to data that can identify any individuals taking part in GlobalMinds.

### Who are you collaborating with?

#### NHS Trusts and Rethink Mental Illness

NHS Mental Health Trusts and Rethink

Mental Illness are helping GlobalMinds to reach people who are eligible to take part in the programme. Researchers at our the NHS can also apply to access GlobalMinds to power mental health research.

#### Academic collaborators

Cardiff University and the National Centre for Mental Health are providing expert expert guidance and support around working with genetic data, based on a long history of research into mental health to help us make GlobalMinds the best it can be.

#### NHS DigiTrials

We're working with NHS DigiTrials, a service that helps invite people to take part in research. They used limited NHS data to identify people who may be suitable for this study and have invited people to take part on our behalf. This was done with special approval from the Confidentiality Advisory Group, which allows contact without consent for this purpose. No identifiable information was shared with the central study team.

Visit our website to find [more information about our funders and collaborators](#).

## 8. Findings from the programme

### How can I hear about the results of GlobalMinds?

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 mental health conditions.

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 feedback about how your individual data has informed discoveries.

### Future opportunities

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

You can say yes or no.



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

If you have any questions, please get in touch at [globalminds@akriviahealth.com](mailto:globalminds@akriviahealth.com) or call 44 (0)330 332 4878.



