

Genetic Links to Anxiety and Depression (GLAD)



Participant Information Sheet

To continue to enrol in the GLAD study you need to read through these pages of information and then complete the consent items at the end.

Overview page

Depression and anxiety disorders are the most common psychiatric disorders worldwide. To improve our understanding of the genetic risk factors behind anxiety and depression, we need to recruit thousands of participants. We therefore invite you to take part in the Genetic Links to Anxiety and Depression (GLAD) study and to join the largest study of individuals who have experienced or are currently struggling with depression and/or anxiety. The project is led by the National Institute of Health Research (NIHR) BioResource Centre Maudsley, and researchers at King's College London.

Signing up to the GLAD study will involve providing access to your medical records (so we can find out some important clinical information), completing some questionnaires, and giving a saliva sample.

On the website you can see information on a number of research studies that are being carried out aiming to understand the role our genes play on the development and treatment of depression and anxiety. If you decide to sign up to this project you will be able to take part in these studies should you wish to that are not limited to anxiety and depression. You can stop taking part at any time.

1. About the Study

The GLAD study is a project set up to explore genetic risk factors in individuals who have suffered with, or been diagnosed with depression and/or anxiety. The GLAD study is a way for those who have experienced depression and/or anxiety to join the NIHR Mental Health BioResource, an NHS NIHR funded project which is part of the NIHR BioResource for Translational Research. The NIHR BioResource is a national NHS initiative where the aim to collect genetic and clinical data from volunteers to build up a central library of information about people's health. It offers you the chance to take part in ground-breaking research aimed at improving the lives of those not only with depression and anxiety, but other health conditions.

The GLAD study aims to conduct research on mental health and treatment. We will:

- Collect psychological data (questionnaire data) and biological (saliva) samples so that we can learn more about the factors that may influence anxiety and depression.
- Link members' psychological and biological data with their medical records.

The GLAD study also aims to create an online research active group of individuals with anxiety or depression as part of the NIHR Mental Health BioResource. We will:

- Create an online resource of members interested in taking part in research.
- Provide members with information about research projects that they can get involved in.
- Regularly update members on the progress of the research and the contribution that they have made.
- Provide links to pages that provide detailed information on mental health difficulties, the treatments available and where to seek help if it is needed.

We will keep all of your data private. All data use is strictly within the terms of the General Data Protection Regulation (GDPR 2018).

To find out more about what signing up involves, click [next](#).

Click [Download Information Sheet](#) at the bottom of this page for a more detailed description of the project.

2. What's involved?

It is essential that all participants in the GLAD study agree to take part of their own free will and indicate that they fully understand what signing up will mean. There is no obligation to sign up. Once you have provided consent you can unsubscribe at any time.

There are **three steps** to signing up to the GLAD study.

Step 1: Giving consent to take part

- The consent form includes a description of each of the types of activity you might be invited to take part in. It is up to you which ones you consent to.
- We will request access to your medical records. This access has been approved by a committee which reviews and monitors access to clinical records. Your data would only be provided to the GLAD and NIHR BioResource teams and, having been anonymised, to researchers approved by our steering committee.
- We will also ask for your consent to be contacted in the future about other ongoing research studies that may be unrelated to anxiety and depression.

Step 2: Questionnaire data

- We will ask you to complete some questions which will ask about your demographics (e.g. age, gender, and employment situation), emotional wellbeing, health and lifestyle, personality and experiences of depression and anxiety. This will take around 30-60 minutes to complete.

Step 3: Saliva sample

- We will ask you to provide a saliva sample by spitting into a specially designed collection tube. This will be sent to you at home and you can send it back to us using a freepost envelope which we will provide.

- We will extract DNA (i.e. genetic material) from this sample, which will be stored at the NIHR BioResource's Biosample Centre (NBC) in Milton Keynes, without any of your personal details (e.g. name, date of birth, NHS number).

Confidentiality

- The data that you provide will be kept strictly confidential. You will be assigned a unique ID number which is used to link your questionnaire answers and medical records to your saliva sample. This means your data is anonymous; the key that links ID numbers to your personal information is stored securely in our database and can only be accessed by members of the GLAD and NIHR BioResource teams. Everyone working at King's College London has a legal duty to keep personal information confidential.

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To find out more about being a member of the GLAD study, click [next](#).

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3. Should I take part?

Benefits of taking part

- Once you are a member of the resource, you will be able to see information about further optional questionnaires, as well as a number of research studies that you are eligible to take part in. You may also be contacted about studies you may be eligible for that are not only related to anxiety and depression. If you choose to do so, you can sign up to be a participant in up to 4 studies per year.
- There may be no immediate benefit to you in terms of treatment, but you will contribute to knowledge about some of the causes of depression and/or anxiety. This knowledge may lead to better treatment guidelines and improve future care for patients.
- The GLAD study is an information resource for members as well as researchers. With this in mind, you will have access to pages dedicated to providing useful information to members.

Possible disadvantages

- Some of the questionnaires ask about topics which some people might find sensitive, and about experiences of anxiety and/or depression. You do not have to complete any questions that you do not wish to.
- Providing a saliva sample is a very low risk procedure but some people find it unpleasant.
- Your participation is strictly confidential and the risk of identifiable information being accidentally disclosed is extremely low.

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4. Final details

What will my information be used for?

Your information will only be used for scientific research purposes. Access to your anonymised data and saliva sample may be made available to other scientists under strict and confidential legal data-sharing agreements. All requests for access to use the data will be reviewed by either steering committees from the GLAD study team or the NIHR BioResource. Any data released to other researchers will be anonymised using your unique ID number, and will contain no personal information.

Will I get information about my genetic results?

The NIHR BioResource Centre Maudsley does not plan to routinely feedback any genetic results obtained from your sample. The results are general for research purposes only, and thus are not for clinical diagnosis or treatment. **In the extremely rare instance that we do find something that is of known clinical importance, we will write to your GP recommending further investigation, if you wish.**

Can I change my mind?

If you decide to withdraw from the GLAD study then we will, if you request it, remove your data from our electronic databases and destroy your DNA sample. You may also request to be removed from the NIHR BioResource Centre Maudsley and the NIHR BioResource part of the project.

What if something goes wrong?

We do not anticipate that anything will go wrong but if you have a concern about any aspect of this project, please call on 0207 848 1638 (Freephone 0800 634 4504) and leave a message for the GLAD study team who will do their best to answer your questions.

Need more information before consenting? Download the full Information Sheet by clicking the button below.

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To become a member of the GLAD study, click [next](#).

If you would like to contact us, please give us a call on 020 7848 1638, or our Freephone on 0800 634 4504, or if you would like to email us at gladstudy@kcl.ac.uk.

