My Brain, Emotions and Me (BE-ME)

Information Sheet for Parent(s)/Carer(s)

Version 2, 06/10/2023

We would like to invite yourself and your child to take part in some research at the Institute of Psychiatry, Psychology & Neuroscience at King's College London. Joining the study is entirely up to you – before you decide, we would like you to understand why the research is being done and what it will involve.

Please take the time to read this information sheet carefully and discuss it with your family and friends if you want to. Ask us if there is anything that you do not understand and take your time in deciding whether you want your child to take part.

Who are we?

We are a group of researchers from King's College London working on an exciting new study: **My Brain, Emotions and Me (BE-ME)**! This study is part of a wider research programme called RE-STAR (Regulating Emotions – Strengthening Adolescent Resilience), which you may have already heard of.

In RE-STAR we are looking to reduce the risk of depression that can emerge during adolescence - especially for neurodivergent young people with ADHD and/or autism.

What is the purpose of this study?

The **BE-ME** study explores the relationship between the school environment and young people's emotional responses to everyday occurrences that are emotionally challenging. The school environment includes things like the classroom, other students, and teachers. We are interested in understanding the brain mechanisms of young people's emotional responses in different environments. We investigate brain activity using **an electroencephalogram (EEG) machine.**

We are inviting young people aged **11 to 16 years** both **with** and **without** a diagnosis of ADHD and/or autism. This is because we want to compare how **neurodivergent** and **neurotypical** young people are impacted emotionally by situations at school.

The findings from this study will be used later in the RE-STAR programme to develop new interventions to support the wellbeing of young people in school, especially those with neurodivergence.

What is involved?

We will do an initial call to find out if your child is eligible for the study and they are happy to take part. If they are, we will invite them to take part in our study. We will organise an introduction session before the visit as below:

Step 1: Online introduction

We will first set up an online introduction so your child can meet our researchers before the study day. This is an opportunity for your child to ask questions about the study and to get to know us.

Step 2: A visit to our research centre

We will invite your child to our research centre after our online meeting. We likely to organise the session after school time. The visit will take about **an hour**, and your child will need to be accompanied by a parent or guardian.

The visit will consist of three activities. The first two are completed while we record your child brain activities. Your child will have time for breaks in between activities, where they can have a drink or snack, and talk to the researchers or to you.

1. In the first activity, your child will listen to audio that portray day-to-day school situations. They will be asked to rate how each situation makes them feel.
2. In the second activity, your child will listen and respond to some sounds, while watching a silent film.
3. After, we will have a brief interview with your child to ask questions about their experience at the research centre. These questions will be sent to you in advance of the session.

You will need to complete a few questionnaires about your child.

What is EEG?

EEG is a method of measuring the electrical signals that the brain is always producing. It is a perfectly safe, non-invasive, and painless method that uses a “cap” with small sensors to record brain activity. No electricity is put into the body.

The EEG cap that we will use already has sensors built in. Contacts between the EEG sensors and your child’s head scalp are maintained by sponges that are dipped in a saline solution. Therefore, your child’s hair may be damp afterwards. The cap looks like a stretchy net, and you can see an example picture below.

Our researchers, Steve (left) and Eloise (right), are wearing the EEG sensor nets.

Your child may want to bring along a hairbrush or hat. We will provide a separate area for your child to rinse and towel-dry their hair if they wish to do so after the recording.

We will measure your child's head circumference with a tape measure so we can select the right size of cap, and we will help them to put it on.

The EEG recording is performed for research purposes only, and **not** medical purposes. It will not be possible to use the EEG to help diagnose, treat, or manage a particular condition. A researcher will look at your child's EEG output for features relevant to the research project only.

Does my child have to take part?

No. Once you have all the information, it is up to you to decide whether your child should take part. If you agree to take part, we will ask you to sign a consent form allowing your child to participate in this study. You need to understand what the study involves and what it will mean for your child before you can consent, so we will check this with you. Participation or non-participation will have no impact upon your child's education.

Once you have signed the consent form, you can still change your mind at any time, and you do not have to explain why. If you change your mind, this will not affect you or your child in any way. If you decide for your child to take part, your child can withdraw from the research at any time. If your child withdraws, we will retain only the information collected up to that point, and only with your agreement. Before you child participates, we will check that they happy to take part; we will make it clear that participation is voluntary.

Is my child eligible to take part?

Your child cannot take part in an EEG study if they have any of the following:

- A history of head trauma resulting in a loss of consciousness.
- Motor control difficulties (e.g., tics/Tourette syndrome).
- Neurological disorder including epilepsy.
- If they are taking medication that cannot be withdrawn 48h before the study day.

If there is still doubt about your child's eligibility, we can discuss this during our initial phone call.

What are the possible benefits of taking part?

Being part of RE-STAR is an opportunity for you and your child to contribute to cutting-edge research. There is no direct benefit for you or your child. The results of this study will be used to develop supports to improve the wellbeing of young people in secondary school.

Will we receive payment?

Families will receive **£25** as a thank you for your visit to the research centre. Your travel will be reimbursed.

What are the possible disadvantages of taking part?

We will ask your child to imagine themselves in different school-based scenarios aided by text and audio prompts. Some of these will represent situations that are challenging (e.g., having too many homework deadlines or being in a noisy environment) or that are supportive (e.g., having understanding teachers or being in supportive classroom) for neurodivergent young people. The scenarios should not be distressing/triggering but can elicit an emotional response.

These scenarios were created based on our previous interviews with neurodivergent young people. They are also co-designed with our youth researcher panel (Y-RP): young people aged 18-25 years who have ADHD and/or autism.

How will my child's data be handled?

We will need to use information provided by your child for this research project. All information will be kept completely confidential and will not be shared with anyone outside of the research team. The only exception to this rule of confidentiality is if we were concerned that your child was at risk of harm, and we would then discuss this with you. The research team may be obliged to share information with your care team or the relevant authorities if we think that your safety or the safety of a child is at risk.

Your child's data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). Your child's data will be stored in an anonymised way, that is, kept with an ID number, not with any of your personal information like name or address. The interviews will be audio-recorded and transcribed by a member of our research team; any information that might identify your child will be removed from the transcript. We will write our research reports in such a way that no one can work out that your child took part in the study.

We will keep all information about your child safe and secure. Data will be stored with password protected file on a secure restricted access King's College London data storage facility. With your permission, we will keep your contact details until the end of the study (31/08/2025) in order to update you on the study. Once we have finished the study, we will keep anonymised data so we can check the results. We will keep the anonymised data for up to 10 years.

What are my choices about how my child's data are used?

You can find out more about how we use your child's data from the KCL Statement on Use of Personal Data in Research webpage, or by asking one of the research team or emailing us at re-starinfo@kcl.ac.uk

What if I change my mind about taking part?

You and your child can stop being part of the study at any time, without giving a reason. Withdrawing from the study will not affect you in any way. During the six months after your participation, you can request we withdraw your child's data from the study. After this point, you and your child can still withdraw from the study, but we will keep anonymised information from you that we already have as this will likely have been included in the study analysis. If you wish to withdraw from the study, simply let the research team know by emailing re-starinfo@kcl.ac.uk

How is the project being funded?

The study is funded by the UK Research and Innovation (UKRI) Medical Research Council (MRC).

What if something goes wrong?

This study has been approved by **King's College London Research Ethics Committee.** If you have a concern about this study, you should contact The Chair, Health Faculties Research Ethics Subcommittee, rec@kcl.ac.uk.

If something does go wrong, and you are harmed during the research, you may have grounds for legal action for compensation against King's College London, but you may have to pay your legal costs. If you wish to complain formally about the conduct of the project, you can contact King's College London using the following contact information for further advice and information: The Chair, Health Faculties Research Ethics Subcommittee (rec@kcl.ac.uk).

How can I find out about the findings of this study?

We will send you a newsletter with an update on the study and its findings. You can find more information about this study and other RE-STAR research projects on our website: https://www.kcl.ac.uk/research/my-brain-emotions-and-me.

Where can I get help if I am concerned about my child's mental health?

Express your concerns to your child's GP, and they will be able to signpost you to local services. You can also access lots of free resources on the following websites:

www.youngminds.org.uk

www.mind.org.uk

What do I need to do now?

If you are happy for your child to be involved, please complete the online consent form, which will ask you for some contact information for you and others involved in your child's care. If you still have some questions, please email us at re-starinfo@kcl.ac.uk. We are always happy to help!

RE-STAR is funded by:

Regulating Emotions – Strengthening Adolescent Resilience