



## My Emotions and Me: characterising emotion regulation in young people

### Information Sheet for Parent/Guardian

#### Background

The proposed study is part of a wider programme called RE-STAR (Regulating Emotions – Strengthening Adolescent Resilience).

In RE-STAR we are trying to understand the way that young people with a diagnosis of ADHD and/or autism manage their emotions in the face of day-to-day stresses and hassles – something we know they can sometimes find challenging. This is important as we also know that emotion regulation skills are associated with improved wellbeing. The overall goal of RE-STAR, therefore, is to find ways to help young people with a diagnosis of ADHD and/or autism to better manage their emotions and so improve their wellbeing.

In this part of the study, we want to better understand how people with a diagnosis of ADHD and/or autism think and talk about emotion regulation. What aspects of their lives make them react emotionally? How they define emotion regulation (what do they call it)? What strategies do they use to regulate their emotions (how do they do it)? What helps? What makes it more difficult?

Once we have collected their accounts, we will use them to develop a new way of measuring emotion regulation for autistic/ADHD young people. This will be used later on in the RE-STAR project to develop methods for helping young people with autism or ADHD when they experience emotional difficulties.



### **What's involved?**

We are inviting young people from age 11 to 15 years and 11 months with a diagnosis of ASD or ADHD to participate in an interview. This will take place either in our research space at the Institute of Psychiatry, Psychology and Neuroscience, King's College London, at Denmark Hill, or via Zoom.

The interview will be divided into two sessions. Session 1 will last approximately 30 minutes. Session 2 will last approximately 60 minutes. In Session 1, we will explain the study to your child, give them the opportunity to ask questions, and check that they are happy to take part. We will give your child instructions for an activity to do at home before Session 2. This will involve asking them to try and create a drawing, take a photo, or to write something (e.g., a poem) about their ideas and experiences around emotion regulation. We will also provide them with our plan for the next session. In Session 2, we will invite them to share what they've made (e.g., drawing or photo) with us. We will also do some activities and interview them about their emotions and emotion regulation. We will record this session, with your and your child's permission, and the recording will be transcribed by a transcription company called Clear Voice. The transcriptions will be fully anonymised i.e. possible identifiers such as names of family, school and or teachers will be removed.

You will not need to be in the room during your child's sessions, but you should be available close by in case they need assistance.

### **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. You can help us understand the development of young people with ASD and ADHD.

### **Will we receive payment?**

Participating families will receive a £10 shopping e-voucher as a token of our thanks, for each session your child attends (to a total value of £20)

### **What are the possible disadvantages of taking part?**

The interviews will ask your child to think and talk about their emotions, including everyday situations that may trigger difficult emotions. We will also be asking them about positive emotions, and what they find helpful for managing their emotions. These interviews should not be distressing, and our research team are experienced in working with young people.

## **What happens to my child's information?**

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

We follow strict guidelines concerning the use and storage of personal information, compliant with General Data Protection Legislation (GDPR). Your child's data will be stored in an anonymised way, that is, their video recordings are kept with an ID number, not with any of your personal information like name or address. And we will write our research reports in a way that non-one can work out that your child took part in the study. We may wish to publish direct quotes from your child's interview. We will protect their anonymity by not using their name and taking care to exclude any other information that might potentially allow them to be identified from quote.

We will need to use information from your child's medical records for this research project. This information will include your child's:

- Initials
- NHS number
- Name
- Contact details.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your child's data will have a code number instead.

We will keep all information about your child safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. We will keep the data for up to 10 years.

## **What are your choices about how your information is used?**

- You and your child can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

## **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)

- our leaflet available from [www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research](http://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research) (KCL) or <https://www.slam.nhs.uk/about-us/privacy-and-gdpr> (SLaM)
- by asking one of the research team
- by sending an email to [info-compliance@kcl.ac.uk](mailto:info-compliance@kcl.ac.uk) (KCL) or [dataprotectionoffice@slam.nhs.uk](mailto:dataprotectionoffice@slam.nhs.uk) (SLaM)

### What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (email Programme Manager: [susie.chandler@kcl.ac.uk](mailto:susie.chandler@kcl.ac.uk)). If you remain unhappy and wish to complain formally, you can do this through the SLaM Patient Advice and Liaison Service (PALS).

In the event that 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 and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

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

We will send you a newsletter with an update on the study and its findings. And you can find more information on our website: under development.

### Any questions?

Please email us at [re-starinfo@kcl.ac.uk](mailto:re-starinfo@kcl.ac.uk) and we would be very happy to help!

You can also visit our website: <https://www.kcl.ac.uk/research/my-emotions-and-me>

