







My Emotions and Me Over Time (MEMO): A longitudinal study of emotional responding in young people.



Information Sheet for Parent/Guardian

Background

We are a group of researchers from King's College London and South London and Maudsley (SLaM) NHS Foundation Trust, working on an exciting new study called My Emotions and Me Over Time (MEMO). This is part of a wider programme called <u>Regulating Emotions—Strengthening Adolescent</u> Resilience (RE-STAR) which you may already have heard of.

In RE-STAR we are looking to find ways to reduce the risk of mental health problems that can sometimes emerge in adolescence. In MEMO, we are exploring which factors are associated with good and poor mental health during adolescence. To do this we are following up a large group of young people in mainstream schools over the course of a year. This will help us understand:

- what types of stresses and hassles do they experience in their everyday lives?
- how do they respond to them?
- and how does this impact on their wellbeing?

We need your help with this.

The findings from this study will be used later in the RE-STAR programme to develop interventions to support young people at greater risk of developing depression.

What's involved?

A. Information from schools

We will ask your child's school to provide some basic information about your child. This will include how well your child is doing at school and whether he/she receives any additional support. All information from the schools will be treated confidential (private) to the research team. The responses will not be seen by parents, other students, teachers or any employee of the school.

Parent/guardian and child questionnaires

We are inviting young people (11-16 years), and their parents/guardians to complete some <u>online</u> <u>questionnaires in Qualtrics at three timepoints over the course of a year</u>. The questions will ask about day-to-day stresses and hassles your child may experience, life events, and how they respond and manage their emotions in relation to these. The questionnaires can be completed at home on a phone, tablet or a computer. We recommend that you be on hand when your child completes their questionnaire in case they need any support. The questionnaires will take young people approximately 60-90 minutes to complete, although the time required to complete the questionnaires will vary from person to person. The parent questionnaires will be fewer in number

(taking about 10-40 minutes). We will ask you and your child to complete these questionnaires at 0-months, 6-months and 12-months from the date you consent to the study.

If you or your child prefers, a researcher can complete the questionnaires over the telephone with you, or you can come into our research centre. If the school allows, the young people may also be able to complete the questionnaires at school.

We may also contact you in the future about any follow-up RE-STAR activities that you and your child have the opportunity to be involved in.

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 how to improve the wellbeing of young people in secondary school.

Will we receive payment?

Participating parent/guardians will receive a £20 e-voucher for the first set of questionnaires as a token of our thanks. A £10 e-voucher will also be sent to parents/guardians for each of the following two sets of questionnaires (i.e., at 6 months and 12 months from the date of consent). The young people will receive separate bonus e-vouchers at the end of the study, as a thank you for completing each of their three questionnaires over one year (£5 bonus for first timepoint + £20 bonus for second timepoint + £20 bonus for third timepoint).

What are the possible disadvantages of taking part?

The questionnaires will ask your child to think about their emotions, including everyday situations that may trigger difficult emotions, as well as major life events. We will also be asking them about positive emotions, and what they find helpful for managing their emotions. These questionnaires should not be distressing; our research team are experienced in working with young people and are more than happy to answer any queries or concerns you or your child may have. If your child does find any of the questions distressing, they can stop taking part at any time, take a break and return to the questions later, and we will signpost young people to support organisations that may be helpful. We would recommend that you be available to your child whilst they complete the questionnaire in case they need any support and check in with them after they have finished the questionnaire.

We do not anticipate any disadvantages or risks to parents/guardians involved.

There is a time commitment required to take part, but the questionnaires can be completed at home via our online platform at the time that suits you and your child. We hope that this will minimise the impact on your daily lives as much as possible.

What happens to your information?

We will need to use information provided by you and your child for this research project and any student projects attached to the study. 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 you or your child was at risk of harm, as a result of something they disclose (which could include disclosures about parents/guardians). 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 will ask you for contact details of your family doctor when you begin.

We follow strict guidelines concerning the use and storage of personal information, compliant with General Data Protection Legislation (GDPR). Your 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. We will write our research reports in a way that non-one can work out that you or your child took part in the study.

We may need to use information from your child's medical records for this research project (e.g., to check if they have a diagnosis of a developmental or mental health condition that might be relevant to the study). 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 13 years.

What are my choices about how my information is used?

- You 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 I find out more about how my information is used?

You can find out more about how we use your information:

- at 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 (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 Olenka Cogias, <u>info-compliance@kcl.ac.uk</u> (KCL) or <u>InformationGovernance@slam.nhs.ukmailto:</u> (SLaM)

What if something goes wrong?

The study has been approved by the Health & Social Care Research Ethics Committee A (HSC REC A). 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). If you remain unhappy and wish to complain formally, you can do this through the SLaM Patient Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk. 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. You can find more information on our website: https://www.kcl.ac.uk/research/my-emotions-and-me-over-time

What do I need to do now?

If you have understood what we are asking and you do not have any more questions, please decide if you want your child to take part in our study. This is entirely up to you. It's OK if you don't want your child to take part and you do not have to explain your reasons. You are also able to change your mind and stop your child taking part at any time.

If you are happy for you and your child to be involved, please complete the online consent form. It will ask you for some contact information for your child, your family and other involved in your child's care.

Any questions?

Please email us at re-starinfo@kcl.ac.uk and we would be very happy to help!

RE-STAR is funded by:

