Companion Information Sheet For Adults

UCL Research Ethics Committee Approval ID Number: 19533/002

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Emotional responses and their relationship with features of ADHD

Department: Institute of Cognitive Neuroscience, UCL

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1. **Invitation Paragraph**
   You are being invited to participate in a research project. Before you consent to participate in the study, it is important that you understand why the research is being undertaken and what participation will involve. Please take time to read the information and feel free to ask the if there is anything that is unclear or that you would like more information about. Take time to decide whether you wish to participate or not. Thank you.

2. **What is the project's purpose?**
   Attention-Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental condition. Everybody has some level of ADHD traits, even people without the condition. In this study, we will measure peoples' ADHD traits using questionnaires. We will investigate whether ADHD traits are associated with differences in emotional responses and whether differences in bodily signals (heartrate, skin conductance [a measure that can determine the sweat responses of the skin], and beat-to-beat blood pressure) might underly them. Specifically, this study aims to understand how bodily responses influence emotional responses involved in empathy, and how this changes with different levels of ADHD traits.

   Participants in this study have been asked to find a companion (friend, family member, or partner) who would like to take part in the study. Someone you know has approached you to complete the study with them. If you would like to proceed with the study, you will both be invited to attend an in-person testing session together.

   During the in-person testing session, you will both complete some questionnaires and small devices (electrocardiogram [ECG], skin conductance unit and beat-to-beat blood pressure cuffs) will monitor your bodily signals (heartrate, skin conductance, and beat-to-beat blood pressure)

while you complete a task together. The devices look like small adhesive stickers with wires coming out of them and will be temporarily attached onto your skin. During the task, you will both receive non-painful electric shocks. This will help us understand emotional responses involved in empathy.

3. Why have I been chosen?

Someone you know (a friend, family member, or partner) approached you to take part in this study with them.

To take part you must be aged 18–64 with normal or corrected-to-normal vision.

The mild electric shocks pose a minor health risk to people with artificial cardiac pacemakers to participate in the study. Therefore if you have a pacemaker, are aged 17 or under, aged 65+, or have impaired eyesight despite wearing glasses/contact lenses, you are not eligible for this study.

We aim to include maximum 150 individuals in this study.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you will be given a copy of this Information Sheet and you will be asked to sign a Consent Form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you withdraw you will be reimbursed in full for your time spent on the study up to that point, either in terms of course credits or financial reimbursement. If you would like to withdraw, please alert the researcher. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

5. What will happen to me if I take part?

<u>Online registration</u>

You will first be asked to complete an online registration form.

<u>In-person testing</u>

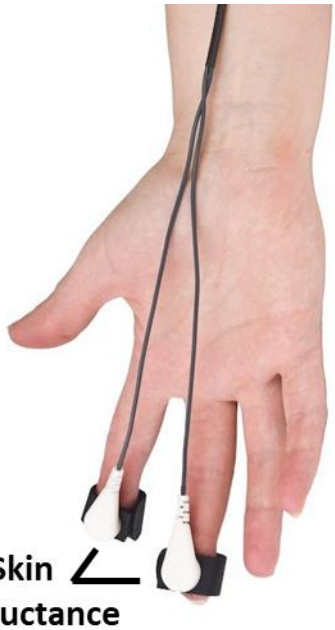
If you would like to proceed with the study, you and the person who approached you to take part in this study with them will be invited to sign up for an in-person testing session. The testing session lasts approximately 1 hour. This can be reduced to approximately 45 mins if either of you have already completed the questionnaires at a previous in-person testing session. The testing session involves the following:

Informed consent

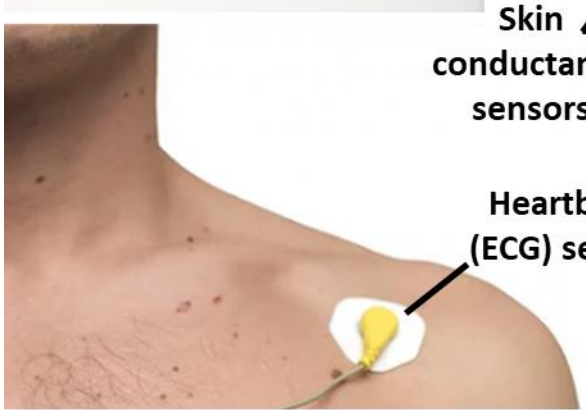
After reading the Information Sheet, you will be invited to sign a Consent Form if you would like to participate.

Equipment setup

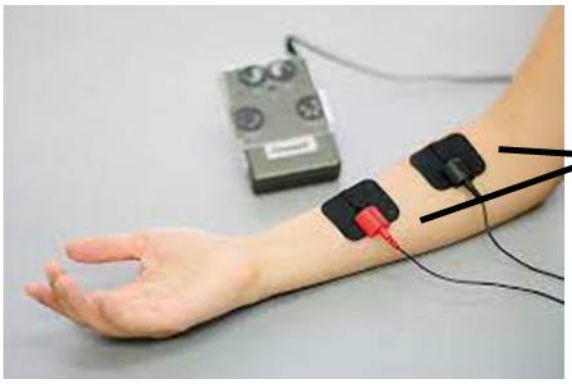
The researcher will attach non-invasive equipment to measure your bodily signals (heartrate, skin conductance, and beat-to-beat blood pressure) and deliver electric shocks. The equipment will be attached to your fingers, wrist and just below the shoulder, similar to these images:



Skin
conductance
sensors



Heartbeat
(ECG) sensor



Electrodes for
delivering
electric
shocks

Tasks
You will be asked to complete a computer-based task with your friend/family member/partner with while your bodily signals are measured.

During the task, you will both receive non-painful electric shocks. The shocks are not harmful. They will be unpleasant but tolerable, similar to a rubber band being snapped against the skin. People differ in their sensitivity to the shocks. Therefore, before the task, the researcher will check with you to make sure the shocks are not too strong for you.

The electrical shocks used in this study will be delivered through two electrodes placed on the wrist. The shock will be delivered by a machine designed for routine human use and which will not shock above safe and ethically acceptable levels. This technique has been used in hundreds of individuals within our research institute with no harmful effects.

Questionnaires
If you have already taken part in an in-person testing session for this study, you do not need to complete the questionnaires again, and the study will only last approximately 45 mins.

You will be asked to complete a series of questionnaires about your thoughts, behaviour, feelings, mental health (depression and anxiety), ADHD traits, current medications, and ADHD diagnostic status.

Data to be recorded
We will record your questionnaire responses, responses on the task and bodily signals.

We will record the following personal data:
- Email address
- First name
- Age
- Sex

We will record the following special category personal data:
- Names of medications you are currently taking for psychiatric or cardiovascular conditions
- Self-reported ADHD diagnostic status

You can withdraw your data at any point up to 8 weeks from today's date.

Future studies
Please indicate on the Consent Form if you would like to be contacted about future research participation opportunities.

6. What are the possible disadvantages and risks of taking part?
The questionnaires contain questions about your emotions and mental health, which some people may find distressing. If any of these questions make you distressed, you may withdraw from the study at any point without giving a reason. If you are concerned about your mental health, please contact the research team, who will be glad to put you in contact with experts on site who are available to chat with you confidentially about your concerns. Alternatively, you may prefer to contact one of the following mental health organisations who provide expert support:

Samaritans
Email: joe@samaritans.org
Tel: 116 123

Mind
Email: info@mind.org.uk
Tel: 0300 123 3393

If you would like to find out more about ADHD, you can find more information on the ADHD UK website https://adhduk.co.uk

The shocks may be unpleasant and uncomfortable, but they will not be painful and have no long-term effects.

There is a risk of tripping over equipment cables. To mitigate this risk, please remain seated while the electrodes are attached to you. If you need to stand (e.g. to go to the toilet), please alert the researcher who will safely remove the equipment.

We remind you that if at any point you wish to withdraw from the study, you are free to do so without giving a reason why or without penalty.

7. **What are the possible benefits of taking part?**
Whilst there are no immediate benefits for those participating in the study, it is hoped that you will find the study interesting and that it will contribute to our understanding of ADHD.

8. **What if something goes wrong?**
If you have any complaints about the project or the researchers' behaviour, in the first instance you can contact the principal researcher running this project on s.garfinkel@ucl.ac.uk. If you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

9. **Will my taking part in this project be kept confidential?**
All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. As part of routine research practice, we will collect personal data, including: email address, first name, age, sex, current medications, and ADHD diagnostic status. Identifiable data will only be accessible by the core research team and will not be published.

10. **Limits to confidentiality**
Please note that confidentiality will be maintained as far as it is possible, unless during the testing session the researcher hears anything which makes them worried that someone might be in danger of harm, in which case they might have to inform relevant agencies of this.

We would inform you of any decisions that might limit your confidentiality.

11. **What will happen to the results of the research project?**
The results will be published through standard scientific outlets, for example in academic journals, talks, and conference posters. If you are participating in a project run by a student, data may be included in the final submitted report, for example an undergraduate or Masters dissertation, or a PhD thesis. All personal identifiers will be removed before any publications and conclusions will be made based on all peoples' data combined not data from individuals.

If you wish to be given a copy of the report summarising the findings from this research, please provide us with your email when asked to do so on the Consent Form. Your email address will be stored separately from all other data.

Screening data will be stored separately from all other study data. Screening data will be deleted on a rolling basis at least bimonthly. If you indicate on the Consent Form that you would like to be invited to follow-up studies for this project, your screening data will be retained for up to 5 years. This data will be stored separately from all other data.

Your testing session data will be stored on the secure UCL servers for up to 10 years, where it will only be accessible by the core research team. Following publication of any resulting papers, all personal identifiers will be removed from the data. Your de-identified study data may be archived online as "open data" for up to 10 years. "Open data" means the data could be downloaded by anyone with an internet connection and used for any purpose.

12. Local Data Protection Privacy Notice

Notice:
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data.

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:
- Email address
- First name
- Age
- Sex
- Names of medications you are currently taking for psychiatric or cardiovascular conditions
- Self-reported ADHD diagnostic status

The lawful basis for processing your *personal data* will be *"performance of a task in the public interest"*.

The lawful basis used to process *special category personal data* will be for *"scientific and historical research or statistical purposes"*.

Your personal data will be processed so long as it is required for the research project (up to 10 years). We will de-identify (pseudonymise) the personal data you provide and will delete the videos at the end of the testing session. We will minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

13. Who is organising and funding the research?

This research is being organised by the Clinical and Affective Neuroscience group at the UCL Institute of Cognitive Neuroscience. The research is funded by the Medical Research Council, grant code: MR/N013867/1.

16. Contact for further information

If you would like to know more information about the study, please contact the researcher or Principal Investigator using the contact details at the top of this Information Sheet.

Thank you for reading this information sheet and for considering to take part in this research study.
