# Participant 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

**Name and Contact Details of the Researcher(s):**
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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 participants' 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], beat-to-beat systolic and diastolic blood pressure) might underly them. Specifically, this study aims to understand how bodily responses to emotional information influence a) attention, and b) emotional responses during social interactions, and how this changes with different levels of ADHD traits.

   There are two stages in this study. The first involves completing a small number of screening questions online lasting approximately 3 mins and without compensation. If you are shortlisted and would like to proceed with the study after screening, you will be invited to take part in the main part of the study: an in-person testing session.

   During the in-person testing session, you will 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, beat-to-beat systolic and diastolic blood pressure) while you complete computerised psychological tasks. The devices look like small adhesive stickers with wires coming out of them and will be temporarily attached onto your skin. The tasks will involve watching videos that contain mildly stressful scenes (e.g. tight-rope walking), recording videos of yourself talking about your hobbies/interests, and predicting how other people will respond to your video recordings.

**3. Why have I been chosen?**

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

If you 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. Participants are shortlisted for in-person testing based on age, sex, and scores on the screening questions, which measure ADHD traits. We will include a range of people with different scores on the pre-screening questions because we want to include individuals with various ADHD trait scores in our 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 and screening</u>

When you register to participate in the study, you will be asked to complete a short screening questionnaire (lasting 3 mins).

<u>In-person testing</u>

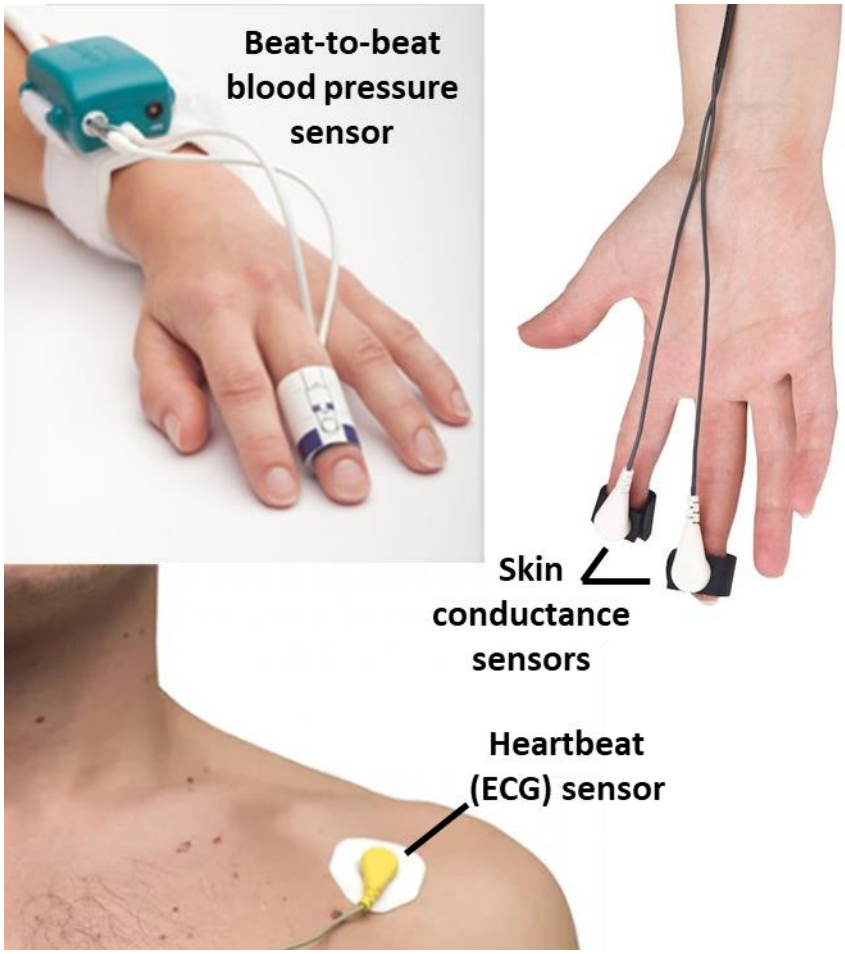
If you are shortlisted (based on your age, sex and responses on the screening form) and decide you would like to proceed with the study, we will ask you to attend an in-person testing session. The testing session lasts 2 hours including a break and involves the following:

*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, beat-to-beat systolic and diastolic blood pressure). The equipment will be attached to your fingers, wrist and just below the shoulder, similar to these images:




*Tasks*
You will be asked to complete two computer-based tasks while your bodily signals are measured.

One of the tasks involves watching short video clips and responding to information on the screen. Some of the videos contain mildly stressful scenes (e.g. tight-rope walking).

In the other task, you will participate in an online game with up to 120 other participants from around the UK. You will be asked to record videos of yourself talking about your hobbies/interests. You will be asked to record roughly 6 videos lasting approximately 12 seconds each. Your videos will be shown to the other participants online, who will provide feedback on the videos. Each other person in the game will watch one of your videos, and you will watch one of their videos. Your task will be to predict how they responded to your video.

*Questionnaires*
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 tasks and bodily signals.

We will record the following personal data:
• Email address

- First name
- Age
- Sex
- Video recordings of you speaking

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. Will I be recorded?**

You will be asked to record short videos of yourself talking about your hobbies/interests. The video recordings will be shown to other participants via a secure online platform. It will not be possible for the other participants to download your videos or record their screen while viewing your videos. The videos will be deleted at the end of the testing session (i.e. today).

**7. 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 feel distressed and/or concerned about your mental health, please notify the researcher, 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

There are no serious risks from performing the computerised tasks or from the equipment for measuring bodily signals.

One of the tasks involves watching short video clips. Some of the videos contain mildly stressful scenes (e.g. tight-rope walking), which some people could find distressing.

One task involves receiving feedback on video recordings of yourself talking. Some people may find this uncomfortable.

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.

8. **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.

9. **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.

10. **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, video recordings, current medications, and ADHD diagnostic status. Identifiable data will only be accessible by the core research team and will not be published.

11. **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.

12. **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 participants' data combined not data from individual participants.

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.

**13. 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
- Videos of you talking
- 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/

**14. 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.

**17. Follow-up study**

We are conducting a follow-up experiment examining bodily emotional responses involved in empathy and their relationship with ADHD traits. We would like to invite yourself and a companion (friend /family member/partner) to attend another in-person testing session at the same location lasting approximately 45 mins. You and your companion will complete the experiment together and will both be reimbursed £9 per hour for your time. If you would like to take part, you will need to find a companion (friend/family member/partner) who would like to attend the in-person testing session with you.

Please indicate on the Consent Form whether you could like to participate in the follow-up experiment with a companion.

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

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