**Parent Information Sheet**

**Study Title**: Is interoception associated with alexithymia and anxiety in autistic adolescents?

**Researcher**: Lauren Craik

**ERGO number: 79622**

Your child is being invited to take part in the above research study. To help you decide whether you are happy for them to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide. You may like to discuss it with others, but it is up to you to decide whether or not they can take part. If you are happy for them to participate you will be asked to sign a consent form on behalf of your child.

**What is the research about?**

I am a current trainee educational psychologist at the University of Southampton completing this research project as part of my doctorate qualification. The research aims to help add to our understanding of anxiety in autistic young people by exploring two factors that have been shown to be related. Firstly, the research aims to explore the relationship between interoception, an individual’s perception of their internal bodily signals (for example, recognising hunger and thirst), and anxiety. Secondly, the study aims to explore the relationship between anxiety, interoception, and alexithymia (a difficulty recognising and describing emotions). These factors have been shown to be related in autistic adults but there is limited research exploring the association in adolescents.

**Why has my child been asked to participate?**

As part of the research all autistic adolescents (both those with a diagnosis and those that self-identify) in participating secondary schools, sixth forms, and colleges are being asked if they would be willing to take part in the study.

**What will happen to my child if they take part?**

* The study involves completing a series of questionnaires that can be completed online at home or during the session with the researcher and should take a total of approximately 20-30 minutes: 1) A questionnaire measuring how sensitive you are to your internal bodily states, with statements such as “when I am tense, I notice where the tension is located in my body”. This questionnaire is answered by rating yourself on a scale of 0 (never) to 5 (always). 2) A questionnaire about identifying and describing feelings with statements such as ‘I find it difficult to say how I feel inside’. Participants answer each statement with not true, sometimes true, or often true. 3) A short questionnaire with 7 questions about autism traits for example ‘Do you or do other people feel that you have very set routines or that you are very immersed in your own interests?’ with participants being asked to respond with not true, somewhat true, or certainly true. 4) A short questionnaire to collect basic information such as date of birth and any medical conditions.
* Following the completion of the above questionnaires, participants will meet with the researcher at their school. They will be made aware of the time and date and will be given a profile of the researcher prior to this. Before taking part, participants will have the opportunity to ask any questions. The following activities will then be completed:
* Participants will be given a questionnaire consisting of 7 statements about anxiety and will be asked to indicate how often they have experienced these symptoms, for example ‘Over the last two weeks, how often have you been bothered by the following problem – Trouble relaxing’
* Interoceptive sensitivity will be assessed using a test where they will focus on their heartbeat. This test includes two short tasks, each lasting around 10 minutes. First, in the Heartbeat Counting Task, they will be wearing a pulse oximeter on their index finger which will record their pulse continuously. While their pulse is being recorded, they will be asked to silently count their heartbeat without manually checking their pulse. There are six trials in this task and at the end of each trial, they will be asked to report how many heartbeats you counted and how confident they are that they answered correctly. The second task, the Heartbeat Discrimination Task, will involve them listening to their own heartbeat whilst wearing headphones. The headphones will present auditory tones which will sometimes match their heartbeat and on other times be slightly out of sync with their heartbeat. After each trial, they will be required to decide whether the tones presented were in or out of sync with their heartbeat. There are 20 trials in this task. These tasks will take approximately 25 minutes in total to complete.

At the end of the experiment, participants will be provided with a summary sheet of the study and will receive a £10 voucher for their participation.

**Are there any benefits to my child taking part?**

Anxiety is a difficulty commonly faced by autistic adolescents and the role that interoception and alexithymia play in this is under-researched and not well understood. Their participation will contribute towards the understanding of how alexithymia and interoception are associated with anxiety in this population, which will to facilitate the exploration of alternative avenues of support and the development of interventions for autistic adolescents experiencing anxiety.

Participants will also receive a £10 voucher for their participation.

**Are there any risks involved?**

We ask that participants do not take part if any of the following are true:

* They have a cardiac condition or cardiac anxiety
* They are taking medication that alters their cardiac functioning
* They are diagnosed with Raynaud’s Syndrome

This is because any of the above can impact the way they feel during participation and may also impact their actions and responses to the tasks.

It is possible that participation in the study could lead to some anxiety for participants due to the researcher being an unfamiliar person and the change to routine. To minimise potential anxiety, the following actions will be taken:

* It can be arranged for someone familiar to participants, such as a friend or staff member, to be present for at least part of the session if this would make them feel more comfortable. They can also bring along any objects (e.g., fidget toys) that would make them feel more comfortable during the session.
* Participants will be made aware of the time and date the research will be taking place prior to the session.
* The information sheet will include clear information about what the study involves, why it is being conducted, and exactly what it will involve. Where appropriate, pictures will be included in the information provided to participants (e.g., example photo of a pulse oximeter)
* Participants will be informed that they can take a break at any time during their participation and a pre-planned break will be arranged for halfway through the process for those who wish or need it.
* A profile of the researcher, including a picture, will be provided to participants.

It is possible that answering questions related to potential areas of difficulty may be upsetting to participants. It is hoped that answering these questions at home, where they feel most comfortable, will minimise this. However, participants will also be directed to avenues of support should they require this.

**What data will be collected?**

We will collect demographic information such as their date of birth. We will record their responses from the questionnaires and from the interoception tests.

All data collected will be anonymised by assigning a unique ID number. A spreadsheet that contains their name and demographics will be password protected and stored securely on OneDrive. Physiological and performance-related data will be stored in separate data analysis files on OneDrive.

**Will their participation be confidential?**

Your child’s participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about them for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

To ensure confidentiality, participants will be assigned a unique ID number from the point of testing. The ID number will be entered in a password protected spreadsheet together with their name and demographic details. The physiological and performance-related measures will be stored with only their ID, thus ensuring anonymity.

The spreadsheet with their demographic details will be kept in a separate file from the physiological and performance-related data thus ensuring anonymity and confidentiality. Moreover, the data will be averaged across all participants for analysis, and at no point will the researchers disclose any performance measures of you as a single participant that might breach your confidentiality.

**Do they have to take part?**

No, it is entirely up to you and your child to decide whether or not they take part. If it is decided that they do want to take part, you will need to sign a consent form and return it to the school to show you have agreed for them to take part.

**What happens if they change their mind?**

They have the right to withdraw or change their mind at any time without giving a reason and without your participant rights being affected. If they wish to withdraw during the questionnaire stage of the study, please email the researcher Lauren Craik on L.Craik@soton.ac.uk. If they wish to withdraw during the in-school session, they can let the researcher know.

If they wish to withdraw their data after participation, they may do so until the 15/01/2024 by contacting the researcher. If you withdraw from the study after 15/01/2024, we will keep the information that we have already obtained for the purposes of achieving the objectives of the study only.

**What will happen to the results of the research?**

Your child’s personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The information collected during this study will be used to produce the thesis of the named researcher. The people who might read these dissertations in an official capacity are the project supervisor, other members of psychology staff and external examiners. Additionally, the information may be published in academic journals, presented at academic conferences, or used for teaching purposes. Your child’s personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify your child. Data will be analysed as a whole sample and you will have a unique participant identification code assigned to your responses to ensure anonymity. Your data will be securely stored in password protected files using the cloud platform OneDrive.

**Where can I get more information?**

If anything is unclear about the study and you would like further information, please contact the researcher on L.craik@soton.ac.uk

**What happens if there is a problem?**

If you have a concern about any aspect of this study, you should contact the researcher who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

**Data Protection Privacy Notice**

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University’s policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason (‘lawful basis’) to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer (data.protection@soton.ac.uk).

**Thank you for taking the time to read the information sheet, and for considering your child taking part in the research.**