**Participant Information Sheet**

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

**Researcher**: Lauren Craik

**ERGO number: 79622**

You are being invited to take part in the above research project. To help you decide whether to take part, it is important that you understand why the project 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 a parent, but it is up to you to decide if you would like to take part. If you would like to take part your parent will need to sign a form to say they are happy for you to take part.

**What is the research about?**

I am a student at the University of Southampton and I am completing this research project as part of my qualification. My research aims to help better understand anxiety in autistic young people by exploring two factors that may be linked:

1. Interoception: this is when a person senses signals from inside their body (for example, knowing when we are hungry and when we are thirsty).
2. Alexithymia: This is when a person has difficulty describing their emotions.

**Why have I been asked to participate?**

Your school has decided that they would like to be involved in the research project. They have sent out this information to autistic students to see if they would like to take part.

**What will happen if I take part?**

* If you agree to take part, you will be asked to complete some questionnaires. You will be asked if you would prefer to complete these at home or when I visit your school. If you would prefer to complete these at home, you will be emailed a link to complete the questionnaires online. If you would prefer to complete these when the researcher is present, you will be sent this link at a later time. It is up to you when you decide to complete these questionnaires. They will take 20-30 minutes to complete:
1. A short questionnaire asking you some basic information about yourself such as your date of birth as well as asking you about any medical conditions you may have.
2. A questionnaire asking how often you recognise signals from your body, 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).
3. A questionnaire about identifying and describing your feelings with statements such as ‘I find it difficult to say how I feel inside’. You will be asked to answer each statement with not true, sometimes true, or often true.
4. 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?’ for you to respond with not true, somewhat true, or certainly true.
* If you choose to complete these questionnaires at home, I will wait until you have done so and then I will visit you at your college or sixth form. You will be made aware of the time and date of my visit and will be given some information and a picture of me beforehand. You can bring someone with you when I visit you, such as a friend or teacher, if you would prefer. You can also bring anything with you that would make you feel more comfortable during the session. I will give you a chance to ask any questions and let you know that you can take a break or stop taking part at any time, if you want to. We will then complete the following activities:
1. I will ask you to complete another questionnaire with 7 questions about anxiety. You will be asked how often you have experienced specific symptoms of anxiety in the last 2 weeks, for example ‘Over the last two weeks, how often have you been bothered by the following problem – Trouble relaxing?’
2. We will complete two short activities that focus on your heartbeat. The first one is called the Heartbeat Counting Task. This will require you to wear a pulse oximeter on your finger, similar to the picture below, which will measure your pulse. Whilst your pulse is being measured, I will ask you to silently count your heartbeat without checking your pulse. We will do this six times and each time you will be asked how many heartbeats you counted and how confident you are that you answered correctly. The second task is called the Heartbeat Discrimination Task. This involves you trying to listen to your heartbeat whilst wearing headphones. You will hear tones through the headphones which will sometimes match your heartbeat and sometimes not. We will do this 20 times and you will be asked whether or not the tones matched your heartbeat. I will also ask you again how confident you are that you answered correctly. Whilst completing these tasks you will need to sit still, but this will be for no more than 1 minute at a time. These tasks will take approximately 25 minutes in total to complete.

 

When you have finished taking part I will provide you with a summary sheet about what we have done and you will be given a £10 voucher to thank you for taking part.

**Are there any benefits to me taking part?**

Anxiety is a difficulty faced by many autistic adolescents and the role that interoception and alexithymia play in this is not fully understood. Your participation will contribute towards understanding how these factors are associated with anxiety and help identify other ways to support autistic adolescents.

You will also receive a £10 voucher for taking part.

**Are there any risks involved?**

You should not take part if any of the following are true:

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

This is because any of the above can impact the way you feel when taking part and may also impact your responses to the tasks.

I recognise that it is possible that taking part in the study could lead to some anxiety as I am an unfamiliar person and it will result in a change to routine. To reduce this, I will do the following:

* I will let you know that you can bring along a familiar person, such as a friend or teacher, and any objects that would make you feel more comfortable during the session.
* You will be told the date and time of my visit before I visit.
* I will remind you that you can take a break at any time and that you can stop taking part if you would like to.
* I will send you a profile of myself with a picture prior to my visit.
* You can complete most of the questionnaires at home.

It is possible that answering questions related to potential areas of difficulty may be upsetting. It is hoped that answering these questions at home will minimise this. However, you will also be reminded who you can speak to if you would like to speak to someone.

**What data will be collected?**

I will collect demographic information about you such as your date of birth and I will record your responses to the questionnaires and to the heartbeat tasks.

All data collected will be anonymised by assigning a unique ID number. A spreadsheet that contains your name and demographics will be password protected and stored securely on OneDrive. All other data will be stored in separate files on OneDrive.

**Will my participation be confidential?**

Your participation and the information we collect about you will be kept strictly confidential.

Only members of the research team and members of the University of Southampton and other authorities whose job it is to check that the research is being carried out correctly will be given access to the data. All of these people have a duty to keep your information confidential.

To ensure confidentiality, you will be assigned a unique ID number. The ID number will be entered in a password protected spreadsheet together with your name and demographic details. Data from the questionnaires and heartbeat counting tasks will be stored with only your ID on a separate spreadsheet to ensure anonymity. These spreadsheets will be kept in separate files and at no point will your scores be disclosed.

**Do I have to take part?**

No, it is entirely up to you and your parent to decide whether to take part. If you want to take part, your parent will need to sign a consent form and return it to your school.

**What happens if I change my mind?**

You can change your mind and stop taking part at any time without giving a reason. If you wish to withdraw during the questionnaire stage of the study, please email the researcher Lauren Craik on L.Craik@soton.ac.uk. If you wish to withdraw during the in-school session, you can let the researcher know.

If you wish to withdraw your data after participation, you 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 already have to achieve the aims of the study.

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

The information collected during this study will be used to produce my thesis. The people who might read this thesis 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 personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you.

**Where can I get more information?**

If anything is unclear about the study and you would like further information, please contact me, 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 taking part in the research.**