

**“*Bridging the gap between autism and eating disorders research*”**

**Participant Information Sheet (Cohort)**

**Neuroanatomical Differences Associated with Anorexia Nervosa and Masking Behaviour in Autistic Individuals**

You are being asked to take part in a research project investigating the relationship between brain structure, eating disorder (ED) symptoms and masking behaviour in Autistic individuals. Masking is a strategy used by Autistic people, whether conscious or unconscious, to ‘blend in’ with neurotypical peers. Masking can produce detrimental effects on Autistic individuals’ mental health and is associated with EDs. This research is conducted by the **Eating Disorders and Autism Collaborative (EDAC)** at the University of Aberdeen, and the study will be headed by Dr Michelle Sader. This research has also been funded by EDAC. Before deciding to take part in this project, it is important that you are provided with information about this research, and what participating will involve. Please do take time to read the following information carefully, and do not hesitate to ask any questions. Contact information is provided at the end of this information sheet. **For your own records**, please do print this sheet, or take a screenshot of the following information.

**What is the purpose of this study?**

This research aims to explore how EDs such as anorexia nervosa (AN) affect Autistic people and to examine any links between masking and ED symptoms. Participants will complete **online questionnaires** about their Autistic traits, ED symptoms, and masking behaviour. To get a clearer picture of how the brain is involved in masking for Autistic people with and without AN, participants will also have a **magnetic resonance imaging (MRI)** **scan**, which is a safe way to take detailed images of the brain.

**Are you eligible to participate in this study?**

You have been invited to take part in this study because you are:

* Between **25-45 years old**
* You are **Autistic** (clinically diagnosed and/or with an AQ-10 score of 6 or higher\*)
* You have **no known history** of trauma affecting the brain (e.g., stroke, chronic traumatic encephalopathy from multiple concussions, etc.)
* You have **no contraindications to MRI**, such as implantable cardiac devices, and are willing to have an MRI scan in Aberdeen
* You can read, understand and respond to questionnaires in English

As participants will need to consent to the study and complete questionnaires by themselves, individuals with intellectual disability will be excluded from this study.

\**Scores on the AQ-10 are in no way intended to make statements on your identity as an Autistic person, rather these scores are used to confirm participant eligibility for this pilot research and ensure good scientific practice.*

**Do you have to take part in this study?**

**You do not have to participate** in this research. Taking part in this study is completely up to you! If you do decide to participate, you will be asked to complete an **informed consent form** at the start to show that you fully understand what is involved and that you want to take part. Within this consent form, you will also be asked to optionally consent to us retaining your contact details for the purposes of sending you a lay summary of the study results and copy of your brain scan once the study is completed.

**What happens if you decide to take part in this study?**

If you decide to take part in this research, you will fill in a series of ten questionnaires that will ask about your age, gender, Autistic characteristics, ED symptoms, how likely you are to focus on a selective or small number of interests and masking behaviour. We will also ask about your levels of anxiety or depression, and any work or social adjustments you may make. After completing the questionnaires, we will ask you to have a brain scan that will last approximately **45 minutes** at Aberdeen Royal Infirmary (ARI). For individuals not local to Aberdeen who may have to travel for this brain scan, the research team is able to offer up to £25 to compensate individuals for travel to ARI. You may choose to complete these questionnaires either online, or during your in-person visit to the ARI alongside your MRI scan. During your MRI scan, you will be asked to lie flat on a bed, which is moved into the middle of the scanner. A picture of the MRI scanner we use can be seen below:



The MRI can be quite noisy but we will provide you with ear plugs and ear defenders to protect your hearing. We can also dim the lights of the scanner room to make the environment more accessible and comfortable for you. If you have a fidget toy or comfort object that does not contain any metal, you may be able to bring it with you to hold during your scan. If it is unclear what material your fidget toy or comfort object is made of, radiographers may need to confirm that the object does not contain any metal before your scan. You will be able to speak to the radiographer the entire time. If you need to stop for any reason, we will bring you out of the scanner as needed. You will be given a call button that you can squeeze at any time if you would like to stop the scan and be taken out.

For some individuals, the enclosed tunnel/space associated with the MRI can bring about feelings of anxiety. We will immediately remove you from the MRI if you feel uncomfortable in any way. More information associated with receiving an MRI can be found on the NHS website [**here**](https://www.nhs.uk/conditions/mri-scan/). In total, we expect the whole process to last **3 hours** including the time to complete the online questionnaires, however the scan will only last **45 minutes**.

With your permission we will inform your GP that you are taking part in this study.

You will be compensated for your participation in this study in the form of a £30 Amazon or Love2Shop voucher, depending on your preference. After participation, you will also be asked to complete an optional feedback survey on your experience participating in the study.

**What are the benefits of participating?**

There are no benefits to you individually but by providing your answers to the questionnaires, and by having a brain scan, you will be helping EDAC **understand the role an ED plays in Autistic people**, and whether masking behaviour is associated with ED symptoms. Understanding these differences in Autistic people with an ED relative to Autistic people without an ED will help health services plan how to improve ED interventions for the Autistic community.

**Are there any risks associated with participating?**

There are minor risks to an individual’s level of anxiety, as the MRI can bring about **discomfort** due to the noise associated with a scan, or the enclosed space an individual will need to lie within during the scan. The MRI also uses magnets to visualise the human body, as such it is important to inform the research team if you have any **metal implants**, **pacemakers** or other **electronic devices** in your body. This does not include passive metal implants, such as aneurysm clips or catheters, that do not need an external power source to work. There is also a very rare occurrence that we may **notice** something in your scan that may require further attention or support from health services. Prior to your scan, you will complete an MRI safety sheet to ensure you are safely able to undergo an MRI scan. If there is any uncertainty with which a participant may be pregnant, they will be withdrawn from the study.

**What will we do if we notice something in your scan?**

The MRI scans taken for this research project are not the same as those that would be needed for clinical diagnostic purposes. However, in the event that the radiologist collecting the scan notices something of medical relevance, a relevant health professional will **discuss these findings with you** and will pass this information onto a relevant health professional if required. If you agreed, we would also inform your GP.

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**What if you no longer want to participate?**

You have the right to withdraw from this study **at any point** of the research process by either not responding the online questionnaires that have been sent to you, or by emailing the study principle investigator (michelle.sader3@abdn.ac.uk). Data collected up to the point of your withdrawal will be retained and used in the study.

**Data protection and confidentiality**

Information and data generated from this study will be collected and processed in line with Data Protection Laws adhering to the University of Aberdeen’s Data Protection policies. All personal data will be kept **strictly confidential**, with pseudonyms or numerical codes used to protect your identity. Personal information (e.g., names, locations, etc.) will be removed from data analysis, with other personal data recorded for the purposes of research (e.g., age, gender, location, etc.) stored on University of Aberdeen servers, which are **encrypted** and **password protected**. MRI scans will also be stored on University of Aberdeen servers, and can be made available to individual participants upon request. De-identified data and scans will be stored for a **minimum of 10 years** on an online data repository, and may be used by other researchers for ethically approved, autism-affirming research.

The University of Aberdeen will act as **the data controller** for this study, meaning we are responsible for taking care of the information you have provided in order for you to participate in this study, and using it properly with regards to protection of your privacy. Contact information (e.g., email addresses), will be retained until the end of the study, and deleted afterwards. If you have agreed to being contacted for future ethically approved studies and deleted afterwards. If you have agreed to being contacted for future ethically approved studies, we will keep your contact details for 5 years.

More information regarding the protection of your data may be found [**here**](https://www.abdn.ac.uk/staffnet/governance/data-protection-6958.php).

**How will we use information about you?**

We will need to use information from you for this research project as detailed below. The University of Aberdeen is the sponsor of this research, and is responsible for looking after your information. General information about you will include:

* Your name
* Contact details (such as your email, address and phone number)
* Demographic information (such as your age, gender, education level, employment)
* Questionnaire-based information covering levels of: ED symptoms, Autistic characteristics, selective interests, Autistic masking, depression, anxiety, co-occurring ADHD, work and social adjustment, psychological trauma

Medical information about you will include information on autism and AN diagnoses, co-occurrence of other physical, mental health and psychological conditions, information on current medication and history of trauma affecting the brain.

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 data will have a code number instead.

We will keep all information about you safe and secure by:

* Handling it confidentially
* Ensuring all aspects of data collection and data analysis comply with existing UK Data Protection Laws.
* Ensuring we protect all of your identifiable and unidentifiable information by using password-protected servers for data in online format, and locked storage cabinets only accessible to the research team for data in paper format.
* Ensuring that any results of this research made publicly available will not contain any personal data that would identify you in any way

Your data will not be shared outside the UK.
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 your study data for a maximum of 10 years. The study data will then be fully anonymized and securely archived or destroyed.

**What are your choices about how your information is used?**

* You can stop being part of this study at any time, without giving a reason, but we will keep information about you that we already have
* You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this
* If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. This data will be stored within secure University of Aberdeen servers

**Where can you find out more about how your information is used?**

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK.

* at www.hra.nhs.uk/information-about-patients/
* by asking one of the research team
* by sending an email to dpa@abdn.ac.uk or
* by ringing us on 01224 272596
* at [www.abdn.ac.uk/about/privacy/](http://www.abdn.ac.uk/about/privacy/)

**What will happen with the results of this study?**

The results of the study will be used to inform on **brain structure** and **function** specific to **Autistic individuals** with versus without **AN**. This will involve dissemination of findings from this study on the EDAC website ([edacresearch.co.uk](file:///C%3A%5CUsers%5Csader%5COneDrive%20-%20University%20of%20Aberdeen%5CApps%5CDesktop%5Cedacresearch.co.uk)), as well as via a publication published on a peer-reviewed journal. All findings from this research will be made available using open-access means, and can be accessed by anyone. It will not be possible to identify you from any publications.

**Who has reviewed this study?**

This study has been reviewed and received ethical approval from the St Camberwell Giles REC.

**Who am I able to contact?**

If you wish to take part in this study or have any questions, please contact Michelle Sader via the following information:

Dr Michelle Sader Michelle.sader3@abdn.ac.uk +44 (0) 1224 38365 School of Medicine, Medical Sciences and Nutrition The University of Aberdeen Lilian Sutton Building Foresterhill Campus Foresterhill AB25 2ZN

If would like additional information about the study, you can also contact:

Dr Gordon Waiter g.waiter@abdn.ac.uk +44 (0) 1224 438356 School of Medicine, Medical Sciences and Nutrition The University of Aberdeen Lilian Sutton Building Foresterhill Campus Foresterhill AB25 2ZN

If you have any complaints about this study, you can file a formal complaint by contacting the NHS Grampian Feedback Service:

NHS Grampian Feedback Service gram.nhsgrampianfeedback@nhs.scot +44 (0) 345 337 6338 Summerfield House 2 Eday Road Aberdeen, AB15 6RE

**Thank you for considering taking part in this study and for taking the time to read this participant information sheet.**