**PARTICIPANT INFORMATION SHEET**

**Supporting Autistic Adults with Eating Disorders: A Survey and Thematic Analysis Highlighting Perspectives Towards Development of Autistic Peer Support.**

You have been invited to participate in a research study examining the perspectives of Autistic people on peer support within the context of their eating disorder (ED), as well as the perspectives of parents or carers and of Autistic children with an ED on peer support programmes to connect with others in similar positions. This research is conducted by the **Eating Disorder and Autism Collaborative (EDAC)** at the University of Edinburgh, and the study will be headed by Dr Michelle Sader and Nicola Llowarch. Before deciding to take part in this project, it is important that you are provided with information concerning the purpose of 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 will be provided at the end of this sheet for any questions. **For your own records**, please do print this sheet, or take a screenshot of the following information.

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

Peer support includes a wide range of approaches by which people with similar experiences or conditions support and/or share knowledge with one another in order to better their understanding their own health experiences, improve their management of recovery from a condition, or assist with managing day-to-day life. Peer support is becoming increasingly popular as an approach within areas of mental health services. There is evidence to suggest that Autistic peer support could be a valuable mechanism for supporting Autistic people with an eating disorder (ED). This research aims to explore what Autistic people think about peer support in the context of their ED to help shape autism-affirming peer support programmes. At the same time, this research aims to gather the views of parents/carers of Autistic loved ones with an ED to understand if a peer support programme could benefit parents/carers.

**Why have I been INVITED to take part?**

You have been invited to take part in this study as you fulfil criteria for this research. This means you are:

* aged **18+** **years**
* **Autistic** (either formally or self-diagnosed) with current living or previous lived experience of an ED **OR** a parent/carer of an Autistic child or adolescent with current living or previous lived experience of an ED
* You are fluent in verbal/written English for the purposes of engaging with questionnaires and an online survey

**Do I have to take part?**

**You do not have to participate** in this research if you do not want to, and taking part in this study is completely up to you! If you do decide to take part, you are still free to withdraw at any time and without giving a reason. You can also refuse to answer any specific question(s) in the survey. Deciding not to take part or withdrawing from the study will not affect your medical care or legal rights.

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

Prior to receiving this participant information sheet, you will have completed an initial screener to determine your eligibility for this study. As we seek to adequately compensate all participants if they choose to receive vouchers for their time taking part, this screener also ensures that the study does not surpass this recruitment limit. You have received this participant information sheet as we have contacted you and confirmed your eligibility to participate in this study.

If you do decide to participate, you will be asked to complete an **informed consent sheet** prior to any steps in the research process, in order to demonstrate that you fully understand the purpose of this study, and that you indeed want to take part.

You will be asked to complete a series of online questionnaires typically used in research studies. Alongside asking questions about your demographic characteristics (e.g., age, ethnicity, etc.), we will use the Autism Spectrum Quotient (AQ-10) to capture Autistic characteristics, the Eating Disorder Examination Questionnaire (EDE-Q) to evaluate ED symptoms, as well as the Hospital Anxiety and Depression Scale (HADS) and the Leibowitz Social Anxiety Scale (LSAS) to determine levels of anxiety and social anxiety, respectively. If applicable, we will also ask questions about a late autism diagnosis and your experiences related to this, as we find it important to understand whether late-diagnosed Autistic people may benefit more, or differently, from peer support. After completion of questionnaires, we will ask you to take an online survey co-developed by our research team. The survey will ask you to respond to a variety of questions focusing on:

* The purpose of peer support, for example whether for emotional, practical, social and/or specific support needs
* Preferences associated with a peer support programme, e.g. group or one-to-one, in-person or online etc.
* The structure of a peer support programme
* Ideal experiences, material or events associated with a peer support programme
* Challenges and concerns associated with the development of a peer support group

If there are things that you think are important that are not covered by the survey questions, there are free text response boxes to provide you with the opportunity to add further comments. Survey responses will be anonymised in order to protect any identifying information you may disclose within your free text answers. The questionnaires including survey may take up to 1.5 hours.

At the end of completing the survey you will be given a link to a short separate survey to decide whether you would like to receive compensation for your participation. If you would like to receive compensation for your participation, you will enter your email address to receive payment in the form of a £15 voucher. Your email address will not be linked to your answers to the survey in any way.

**What are the POSSIBLE benefits of taking part?**

By providing your answers to administered questionnaires, as well as a survey, you will be helping EDAC provide evidence to support the development of **peer support programmes for Autistic individuals with an ED**. Subject to the outcome of this study, this may lead to future studies examining peer support in practice, to evaluate the potential benefits of an Autistic-led peer support programme with the objective of assessing whether peer support could achieve significant benefits, particularly in supporting recovery from an ED. This may also involve further studies investigating how to facilitate potentially embedding peer support into clinical pathways.

**Are there any risks or disadvantages associated with taking part?**

While the research is not designed to cause distress, we appreciate that thinking about difficult experiences of an eating disorder, and mental health problems such as anxiety may be upsetting. If you experience any distress during the survey or have any other concerns, you have the right to leave and withdraw from the survey by closing the tab, or you can take a break by leaving the web browser tab open and stepping away from your computer. You can speak with or email the study principle investigator, Michelle Sader (v1msadle@ed.ac.uk) before you agree to take part in the study, to learn more about the questions that will be asked and decide whether you want to participate.

**Will my taking part be kept Confidential?**

All the information we collect during the course of the research will be anonymised and kept confidential and there are strict laws which safeguard your privacy at every stage. You also have the right to withdraw from this study **at any point** of the research process by either not responding to the online questionnaires and surveys that have been sent to you, or by emailing the study principle investigator (v1msadle@ed.ac.uk) to notify us and have your contact information deleted from our servers. As your data will be anonymised, we will not be able to delete the survey responses you have provided at the point of your withdrawal.

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

We will need to use information from your survey responses for this research project.

This information will firstly include your sociodemographic characteristics, such as your name, age, gender, contact details, ethnicity, level of education, employment status, medication status as well as your autism and eating disorder diagnostic status. This information will also include information from questionnaires evaluating eating disorder traits, Autistic traits as well as levels of social anxiety, general anxiety and depression. Lastly, this information will include answers on questions referring to your thoughts on peer support programmes for either Autistic people with eating disorders, or parents and carers of Autistic loved ones with eating disorders. People will use this information to do the research.

All personal data will be kept **strictly confidential**, with pseudonyms used to protect your identity as you complete the short compensation survey. Personal information (e.g., names) will be removed from data analysis, with other personal data recorded for the purposes of research (e.g., age, gender, ethnicity, etc.) stored on University of Edinburgh servers, which are **encrypted** and **password protected**. Identifiable information will be stored until you confirm receipt of your compensation. De-identified data will be stored for a **minimum of 5 years** on an online data repository, and may be used by other researchers for ethically approved, autism-affirming research. We will keep all information about you safe and secure, and all data will be anonymised.

All information will be stored on a password-protected online server supported by the University of Edinburgh. If you chose to give us your email address for voucher compensation, this will be kept separate from the rest of your answers. We will not be able to identify which email address is linked to which answers. Contact information (e.g., email addresses), will be stored until confirmation of receipt of your voucher, at which time it will be permanently deleted.

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

* You can stop being part of the study at any time by closing the computer window, without giving a reason, but we will not be able to withdraw your data after completion of the survey as your data will be anonymised.
* We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

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

For further information about data privacy for research participants please click [**here**](https://data-protection.ed.ac.uk/privacy-notice-research), or:

* Ask one of the research team members
* Send an email to the supervisor Dr Michelle Sader – v1msadle@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you and in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you until we receive confirmation of your compensation or unless you withdraw from the study. Your anonymised data will be kept for a minimum of 5 years.

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

The results of the study will help provide evidence to support the development of peer support programmes for **Autistic individuals** with an **ED**. All findings from this research will be made available using open-access means, and can be accessed by anyone.  The results of this study may be summarised in published articles, reports and presentations. You will not be identifiable from any published results. Quotes or key findings will always be made anonymous in any formal outputs. With your consent, your anonymised information may also be kept for future research. The findings of the study will be made available through the publication of undergraduate/MSc dissertations, scientific articles, layperson summaries, as well as presentations at conferences. Dissemination of findings from this study may also be made available on the EDAC website ([edacresearch.co.uk](file:///C%3A%5CUsers%5Csader%5COneDrive%20-%20University%20of%20Aberdeen%5CApps%5CDesktop%5Cedacresearch.co.uk)), and participants may contact the research team to request a summary of the study findings.

**WHO IS ORGANISING AND FUNDING THE RESEARCH?**

This study has been organised by Michelle Sader. It is sponsored by the University of Edinburgh.

**WHO HAS REVIEWED THE STUDY?**

The study proposal has been reviewed by the University of Edinburgh School of Health in Social Science Ethics Committee.

**WHO CAN I CONTACT?**

If you have any further questions about the study, please contact the supervisor Dr Michelle Sader; Email: v1msadle@ed.ac.uk.

If you would like to discuss this study with someone independent of the study please contact Dr Karen Goodall, Senior Lecturer; Email: karen.goodall@ed.ac.uk.

If you wish to make a complaint about the study, please contact:

Prof. Matthias Schwannauer; Email: headofschool.health@ed.ac.uk.

In your communication, please provide the study title and detail the nature of your complaint.

**If you are affected by any of the questions in the survey and feel upset, please contact your GP. In addition, you can also reach out for support from the following networks.**

* Samaritans provides confidential non-judgmental emotional support for anyone who is struggling to cope: call 116 123, or email jo@samaritans.org
* Breathing Space is a free, confidential phoneline service for any individual who is experiencing low mood and depression, or who is unusually worried and in need of someone to talk to: call 0800 83 85 87
* Counselling Directory provides information to help people find a qualified counsellor or psychotherapist in their local area: <https://www.counselling-directory.org.uk/>.
* NHS 24 provides urgent health advice out of hours, when your GP practice is closed: call 111.
* The Autism Helpline of the National Autistic Society offers information and advice for individuals on the spectrum and their families: please call 0808 800 4104 or go to [www.autism.org.uk/enquiry](http://www.autism.org.uk/enquiry).
* BEAT Eating Disorders also offers information and advice for people struggling with eating disorders. Please go to <https://www.beateatingdisorders.org.uk/get-information-andsupport/get-help-for-myself/i-need-support-now/online-supportgroups/>.

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