EDAC

"Bridging the gap between autism and eating disorder research."

Conducting Ethical, Co-produced Research with and for Autistic Individuals with Eating Disorders.

Best Practice Guidelines

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The Eating Disorders and Autism Collaborative (EDAC) are delighted to introduce these *Best Practice Guidelines in Conducting Ethical, Co-produced Research with and for Autistic individuals with Eating Disorders.* These guidelines were developed collaboratively over a series of workshops with clinicians, researchers, and Autistic individuals with lived\living experience of eating disorders; acknowledging that many participants identified with multiple roles.

The belief underpinning these guidelines is that meaningful and impactful research can only be developed in partnership with the community that is most affected by it. We hope to support researchers in this field to realize the benefits of co-production by addressing concerns about historical research and barriers to this process. We were able to develop reflective questions designed to support a research team to facilitate collaborative discussions exploring potential challenges and solutions to developing meaningful research. These reflective questions have been separated into considerations when designing, conducting, and disseminating research and formatted into interactive worksheets to support people to actively participate in these discussions within their own research teams.

This guideline and associated resources are freely available, and we hope will be embraced by those conducting research with and for Autistic individuals with eating disorders.

The EDAC Team

www.edacresearch.co.uk

Best Practice Guidelines for Ethical Co-production in Autism and ED Research

What is Co-production?

Co-production is the development of new research knowledge by all participants working together on a research topic without privileging one form of knowledge over another. It tries to break down the "us and them" distinctions of traditional research, and instead supports the joint production of research and co-ownership of it. Co-production can take place throughout a project, from developing research questions, design and priority setting, governance, co-delivery of research activities, and communication of findings. This provides a platform to support the development of meaningful research, aligned with the needs of individuals and communities.

The Eating Disorders and Autism Collaborative (EDAC).

The Eating Disorders and Autism Collaborative (EDAC) is an innovative project aiming to increase research capacity by supporting research collaborations on the interface between eating disorders (EDs) and autism. EDAC comprises of four integrated workstreams to co-produce inter-disciplinary research, directed by Autistic individuals with lived/living experience of EDs (for more information on EDAC see Duffy and Gillespie-Smith, et al., 2023 or edacresearch.co.uk). This document was developed through the first workstream of EDAC: five workshops were run with Autistic individuals with lived/living experience of EDs, researchers and clinicians (with the recognition that many individuals represented multiple roles) to create guidelines on the ethical co-production of research in the field. Details of these workshops can be found in Appendix 1. Everyone who contributed to the workshops has been invited to co-author these guidelines and are listed as an EDAC member.

Co-production in Autism and Eating Disorder Research.

There is a clear need for co-production in autism and eating disorder research. Our workshops identified that past research has focused on deficit and medicalized approaches to autism and there is a need to acknowledge the harm and mistrust this has created in the Autistic community. There is a clear message from the Autistic community to focus on autism-led research that views autism as a neurotype characterized by differences, not deficits. Within ED research we have seen a bias towards research exploring Anorexia Nervosa; a lack of diversity in the demographic characteristics of researched populations; and most recruitment has taken place in clinical settings without considering the high proportion of individuals are not in clinical services. This has been replicated in ED research in Autistic populations. Furthermore, there

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has been a lack of consideration that while the presentation of ED symptoms or behaviours may be similar to a neurotypical population, that their underpinning processes or functions may be quite different. Finally, it has been suggested that past research has been conducted without clearly identifying how it will improve the lives of Autistic people with EDs. Co-production can navigate these past difficulties by centering research on the priorities of the Autistic and ED community.

Project Goals

The goals of the project were to support the development of more meaningful and inclusive research by:

- Developing a shared understanding of how to collaboratively develop novel, autistic and lived/living experience led approaches to research.
- Co-producing best practice guidelines for achieving this.
- Agreeing a set of principles that will underpin EDAC, its workstreams and any collaborative research aligned with the network.
- Making these guidelines accessible and useful to support adoption by the Autistic and eating disorder research community.

Language

A foundational point raised across the workshops was the importance of using respectful language that all members of the research team can understand. We will use identify-first language for autism (Autistic person) as opposed to person-first language (person with autism). This was the consensus amongst the group and is aligned with published recommendations from the broader Autistic community (Kenny et al, 2016; Bury, Jellett, Spoory & Hedley, 2020;

Bottema-Beutal et al, 2021; Monk, Whitehouse & Haddington, 2022). In line

with this, we will use terms such as '*differences*' as opposed to '*deficits*' when discussing autism-specific traits and behaviours. With regards to eating disorder terms, we will avoid the use of terms such as '*anorexic*' or '*bulimic*' to avoid implying that the individual is defined by their eating disorder. We do note, however, that

preferences will vary across individuals, and conversations around language use should be conducted within your own research teams before any decisions are made. Preferences may change over time and language use should be a reflective and ongoing discussion.

Key terms

The following section will outline common research terms and concepts and provide a definition of each. This is not an exhaustive list and may vary between different contexts and settings.

Co-Production is when researchers and community members work together to produce research as equal partners.

Ethical describes abiding by moral principles and standards.

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways, there is no "right" way of thinking, learning and behaving and differences are not viewed as deficits. A person cannot be neurodiverse, it is a trait of the whole group not an individual.

Neurodivergent is used to describe individuals where their particular way of thinking, learning and behaving may fall out with the prevalent societal norm.

Neurotypical is used to describe individuals where their particular way of thinking, learning and behaving may fall within the prevalent societal norm.

Autism-affirming is a strength- and rights-based practice that promotes and affirms the person's Autistic identity.

Contents

The following document will present ***Best Practice Guidelines for Ethical, Co-produced Research with and for Autistic people with Eating Disorders***. The guidelines emerged from a series of five workshops with Autistic people with lived/living experience of an ED (please see Appendix 1 for more details), and the finalized guidelines have been co-produced.

First, we will make suggestions for **Getting Started** with a research project in the field of autism and EDs, highlighting potential barriers to developing co-produced research. We will provide an over-arching set of **Key Principles for Ethical Co-Production** intended to address concerns about historical research and address barriers to ethical co-production. For the final three sections, we will focus on specific stages of the research process, providing reflective questions designed to support a research team to facilitate collaborative discussions exploring potential challenges and solutions to developing meaningful research. Section 3 will provide reflective questions to support a research team in **Designing Research**, focusing on the process of identifying research questions and how to navigate tensions surrounding what we are measuring and how we are measuring it. Section 4 will provide tools for open discussions on **Conducting Research**, with a focus on considering how to recruit the community and maintain ongoing relationships. We will support this with two case studies to demonstrate this process. The final section will focus on **Disseminating Research** and will provide reflective points to consider how to work together to share accessible research findings with the Autistic and ED community.

Getting Started

This section of the guidelines will suggest key things that you may consider at the start of your research project before you engage in the co-production process. We also recommend you engage in similar discussions at the start of your research project, discussing definitions of co-production, what issues there may be with the existing evidence you are building on, and potential barriers to co-production. This is an essential part of fostering collaborative relationships from the outset, and making sure that your proposed research will be meaningful to the Autistic and ED community.

Benefits and barriers to ethical, co-produced research

Co-produced research has lots of important benefits but there are barriers that may make it difficult to conduct. It is important to consider these potential barriers before engaging with the Autistic and ED community in co-production research, and to think about how to best address these issues.

Benefits

- Co-production enables the community who are going to be most affected by the research, to shape it. This is a moral and ethical stance of "*nothing about us, without us.*"
- Active co-production in the design and implementation of research enables more meaningful research that will be of benefit to the community affected.
- It is important to acknowledge that a previous deficit-based approach to research has created mistrust in the Autistic community. Co-production has the capacity to build trust in the research team.
- It empowers members of the community to be involved in research, learn new research skills, and take an active part in academia.
- It provides valuable new insights to the research team, alongside challenging preconceptions, and stigma.

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Barriers for conducting co-produced research in the Autistic and ED community:

- Researchers being tokenistic or engaging in *'faux production'*, where there is a *'ticking a box'* approach as opposed to engaging in a meaningful way with co-production. *'Dropping in'* on communities when needed rather than building up meaningful relationships and engagement.
- Lack of autism awareness or knowledge amongst research groups, leading to feelings of being misunderstood (e.g., labelled as *'rude'*) and therefore disengaging with the co-production process.
- Autistic people with EDs feeling they show such different presentations of EDs that they may not fulfill stereotypes and/or expectations of researchers. There were reports of not being *'Autistic'* enough or showing different or multiple ED symptoms and presentations.
- The impact of timing of autism diagnosis, and how this might influence the individual's experience of their eating disorder and engagement with research.
- The distressing or potentially triggering nature of taking part in ED research.
- Researchers only engaging with people they find it *'easy'* to communicate, engage or interact with and lack of adaptations to communication to support the process.
- The co-production role is only advertised after the topic has been decided on, often by neurotypical people, and often does not align with the research priorities of the community.
- Lack of trust in researchers after negative experiences
- Unconscious bias, stigma, and dehumanizing language from researchers

Barriers for researchers

- Lack of clear guidance and support for what co-production involves from academic institutions and funders.
- Getting funding to compensate those with lived experience for their time, especially for research students and activities that need to happen prior to grant funding (e.g., the conceptualization of research questions).
- Time. Co-production requires a lot of time investment, and this can have implications on the researcher (e.g., capacity, demand from other projects)
- Concerns about *"getting it wrong"*, the need to support and guide early career researchers who may at times make mistakes in language or positioning of research.

Barriers for both

- Lack of clear definitions of what co-production is and inconsistency in what terms are used (e.g., co-production, participatory research)
- Speaking different languages between researchers and lived experience leading to a '*language barrier*'.
- Unrealistic expectations for both parties on what individuals

supporting co-production can and should do, and researchers maintaining the boundaries and requirements of specific methodologies which then have the capacity to be published and advance the field.

- Differences in knowledge base, researchers expecting the community to have up to date research knowledge.

Overarching Best Practice Principles for Ethical Co-Production

The following principles should be considered for all stages of the research process to support meaningful co-production. Please be aware that the application of these principles will vary across different contexts and settings, and we urge you to reflect on how to best apply these to your research.

1. **Develop a shared understanding of the use of language**. Discuss and agree on acceptable language from the beginning of your project. For example, avoiding harmful and medicalized language when discussing autism, and considering terms frequently misused in the scientific literature on eating disorders (Weissman, et al., 2016). This includes both the use of person-first language in relation to EDs and avoidance of inference of willful intent e.g., "*not engaging*" in treatment, rather than treatment

not being effective. The nuance of language will be dependent on the population you are looking to recruit and should be prioritized early in the co-production process.

2. **Develop a shared research language.** During co-production, communicate using lay language, and encourage each other to highlight when overly technical language is being used or unfamiliar abbreviations or acronyms. However, glossaries should also be provided linked to technical terms,

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empowering the co-production team to explore these topics further if they would want to do so.

3. **Establish clear definitions of co-production.** Definitions of co-production vary between different contexts, and many different terms can be used to describe a similar process. Establishing an agreed definition for your research team is an important first step in the co-production process and can be achieved by discussing the process, principles and how it should feel when co-production is working effectively. Try to develop and communicate these definitions using different mediums (e.g., verbal, visual).

4. **Establish clear roles and expectations.** It is important that all members of the research team clearly understand the co-production process, their roles within it, and that everyone arrives at this understanding together. This reduces unrealistic or mismatched expectations in the research team. Do this from the start of the project and build in review points and feedback loop throughout the research.

5. **Ensure that peer researchers are reimbursed for their time.** It is important that those with lived/living experience are reimbursed properly for their time. However, we need to acknowledge the financial limitations of some research (for example student research projects). Therefore, in certain circumstances, the co-production partnership may want to jointly consider other ways of valuing contributions for example, authorship on publications, reciprocal time or skill exchange. Fundamentally, peer researchers should feel appropriately valued for their time and level of input.

6. **Recruit, recognize and accommodate for the range of Autistic experiences of eating disorders.** The research team should seek to work with a diverse range of peer researchers, considering culture, gender, sexuality, age, socio-economic backgrounds, as well the range of autism diagnoses experiences (self, new, late, adult, childhood, etc.) The research team should particularly be aware of different communication styles and strategies amongst the Autistic and ED community and should make appropriate adaptations. A range of different methods should be made available based on the communication needs of the participants and research team.

7. **Make sure there are wellbeing practices and support in place** for the co-production team. This should be clear and available across all stages of the co-production process.

8. **Involve peer researcher in several co-production roles across all stages of the research process**, including design and leadership roles. Clearly outlines these roles from the outset.

9. **Conduct autism-affirming research.** Be aware of existing biases in research and where possible make pro-active attempts to consider the needs of under-represented populations in autism and eating disorder research.

10. **Seek to improve trust and to foster a shared, collaborative relationship**. Acknowledge potential harm caused by past research and counteract this by being transparent and open in your research aims and purposes. Develop and plan and strategy for a long-term relationship with the community where trust can be fostered, rather than a way to meet the needs of an individual research project.

Reflection on the Research Process during Co-production

The following sections are designed for a research team to work together to reflect on the different stages of the research process. This is to be conducted collaboratively as part of an early co-production process to guide the development of meaningful research in the field of autism and eating disorders. Handouts for these reflective questions can be found in Appendix 2 and can be downloaded via www.edacresearch.co.uk

1. Designing Research

This section of the guidelines will outline the first stage of the research process; designing research. We will outline key sources of tension or possible obstacles for how to ethically co-produce research during the design and development stage. We focused this on the two key areas: (1) Developing research questions; and (2) What we are measuring and how we are

measuring it. This is followed by a list of reflective questions that are intended to be conducted collaboratively within the co-production process and whole research team.

1.1 Developing research questions.

One of the leading barriers to ethical co-production in autism and ED research is failing to include the community in the development of research questions. This means that some research is being designed without considering how it will improve the lives of Autistic people with an ED and is not aligned with the priorities of the community. Often, opportunities for co-production are only advertised after the topic has been decided on (often by neurotypical people without lived experience) meaning the community does not have an opportunity to influence the direction of the research. While we acknowledge limitations of current research processes (for example having to apply to grant funders with defined research questions before being able to pay people for co-production), this highlights the need to build strong and longer-term relationships with the autism and ED communities on an ongoing basis. The following reflective questions are intended to be used within the research team to have open discussions about this process.

Reflective Points for the research team to consider developing research questions.

- How can we engage with the community to **identify gaps within the existing research**, and which gaps to prioritize? This can be via prior work e.g., priority setting work that has already been completed by others in the field.
- **Who is "*round the table*"**? Have we involved the Autistic and ED community from the outset to support in formulating the research purpose, aims and intended outcomes?
- Have we actively looked to **collaborate with individuals with a range of different experiences**? For example, Autistic people with different ED presentations or at different stages in recovery, or Autistic people with an ED from a range of cultural and socio-economic backgrounds Have we supported individuals with different communication needs to take an active part in this process? How can we make sure we do not perpetuate biases in past research by engaging with the same populations repetitively?
- **What are the research priorities of Autistic people with EDs?** Do the priorities reflect a range of experiences and how has our understanding of these priories been collected e.g., reliance on online surveys with can bias experiences towards specific communication styles and those who can access technology. How can we remove

communication barriers and consider the use of different platforms or networks to access a broad range of opinions?

- Are our **research purpose, aims and outcomes clear and transparent**?
- **Will this research benefit the Autistic and eating disorder community?** Have you thought about how this will improve the lives of Autistic people with an ED, and considered if it something that you would participate in yourself? Have you considered what has and what has not worked before, and how to meaningfully build on this?

1.2 What and how to measure autism and eating disorders.

There is a tension between meaningful research aligned with a community's needs, and for a research team to be accountable to expectations of the scientific community. One example would be the need for research to be inclusive of individuals with self-diagnosis of autism and disordered eating (considering lengthy wait lists for autism diagnosis, that a high proportion of individuals with an ED don't access formal treatment, and the wealth of knowledge that under-represented populations can bring to a research process). However, some research journals or study methods may require stringent criteria about defining your population (group of people you are researching), including the potential requirement for diagnoses. There is clearly a need for balance between meaningful research aligned with the community's need and research that will be publishable and impactful. There is also a tension in that many that standardized assessment measures of ED symptoms have been developed primarily on neurotypical presentations, and there are concerns that these fail to be inclusive of Autistic presentations of EDs. The following reflective questions are intended to be used within the research team to have open discussions about this process.

Reflective Points for the research team to consider how and what to measure in the research process.

- **What are the requirements of the specific research design and methodology we are proposing**? Is it essential for formal diagnoses to be part of our inclusion criteria, or are we perpetuating biases (both conscious and unconscious) in research and creating unnecessary barriers to participation?
- Are our inclusion criteria based on using standardized outcome measures (e.g., an individual included in a study if they are over a specific threshold on a measure)? **Are these meeting the communication needs of the population we are recruiting? Is this measure inclusive of the range of Autistic experiences of an eating disorder**?

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- **Are there opportunities to explore individual symptoms, experiences, and underpinning mechanisms of EDs in Autistic people**? Would this approach be more aligned with the communities' research priorities?
- If our research design requires specific approaches that create tension with the communities needs or priorities (e.g. formal diagnosis, recruitment approaches, randomization etc.) how can we acknowledge this as a **potential limitation** and be transparent about why?

2. Conducting Research

This section of the guidelines will outline the next stage of the research process, conducting research. We will outline key challenges and possible sources of tension when conducting co-produced research. This includes recruitment and how to access a broad range of diverse Autistic individuals with EDs, both as participants and as part of the co-production process. We would then encourage research teams to collaboratively reflect on challenges, sources of tension and potential solutions, associated with the specific methodologies they are using in their own research. To support this, we have used two case examples used in our own discussions: brain imaging and art-based approaches.

Reflective Points for the research team to consider when planning how to conduct research:

- **Does our research design and methodology allow us to extend our recruitment strategies to be more inclusive?** For example, are we biasing our research by only recruiting individuals in clinical ED services?
- **Are we actively engaging with under-represented groups and networks?** How can we use co-production to determine the best platforms, networks, and community resources to recruit from? How can we develop meaningful, and longer term, relationships with these networks and community organizations beyond recruitment for this research project?
- **Are there unique needs or experiences of certain groups that we are seeking to recruit?** For example, in some ethnic minority groups it will be very important to consider the different dialogues around food and/or mental health presentations.
- **What are the communication needs of our target population?** How can we make sure we accommodate these needs and make recruitment and the research process as accessible as possible? Are we making adaptations on an individual basis?

- **Have we factored in enough time** to our recruitment process to support meaningful engagement? Have we allowed enough time for individuals to process information and to support informed consent? Have we prepared for extending timeframes if needed?
- How can we **clearly communicate the purpose and intended outcomes of our research** - what we are researching, why we are doing this and how the research could help the community? Will this be communicated in a range of different formats? And have you worked together to co-create this?
- **Can we be visible and transparent with the research process**? How can we make the research team and processes that will take place transparent? Would this process lend itself to using different mediums (text, videos, maps, or venues) to assist people in knowing what to expect?
- **Have we clearly shared all the information needed to collect informed consent?** Have we engaged with the co-production process when approaching this and considering multiple levels within consent? Have we discussed this with the participants and made sure that all questions have been addressed, and that expectations and boundaries are clear?
- How can we be **consistent and clear in communication** throughout the research process? For example, is there a single point of contact, or availability of different methods of keeping in touch with the research team (e.g., email, online, chat function or face-to-face discussions)? Are there regular check-ins and ways to collect ongoing feedback planned?
- **What challenges or sources of tension could there be with our chosen methodologies in the Autistic and ED community**? Are there any ethical concerns with this approach? Are there practical aspects of this technique or methodology that must be considered with this population, for example, environment and sensory stressors? Can barriers to research be reduced?

We have used the following case examples to show how we conducted a "deep dive" into two methodologies as part of EDAC with the aim of supporting readers to think about how to do this with your own chosen methodologies.

Eating Disorders and Autism Collaborative (EDAC) Case Example 1

Co-produced reflections on brain imaging as a research methodology with Autistic individuals with eating disorders

One of the methodologies we are using at EDAC is a type of brain imaging called magnetic resonance imaging (MRI). We wanted to understand any potential ethical concerns associated with research using this technique and to co-produce suggestions on how to mitigate these concerns.   We used the following reflective questions to support us with this process.

- What could the **challenges or sources of tension** be with the use of brain imaging in autism and ED research?
- Are there any **ethical concerns** with this approach in this population?
- Are there **practical aspects** of this technique or methodology that must be considered with this population, for example, environment and sensory stressors?
- Can **barriers to research** be reduced?

The research team identified several tensions with this methodology.

- Many of these concerns centered on the potential for these approaches to be used for screening or eugenic purposes to identify what is "*wrong*" with the Autistic brain. It was noted that a lot of the language used in this field is highly medicalized, frequently exploring "*dysfunction*" and "*deficits*". This is represented by research which frequently compares Autistic versus neurotypical individuals as opposed to, for example, considering Autistic individuals presenting with and without eating disorder symptomatology.

- It is common practice (and sometimes a requirement by funders) to, with consent, anonymize data at the end of brain imaging studies so is made available via open access by other researchers in the field. Concerns were raised that while this was best research practice, the aims of future research using this data will not be communicated to participants and may not be aligned with a neurodiverse-affirming approach.

- The research team was able to identify several environmental and sensory stressors associated with the noise of the MRI process and that it requires being still for a prolonged period, meaning individuals were unable to have movement breaks or stim. This also has potential implications as this technique will then bias data collection towards those that can tolerate this research process.

Case Example 1 (cont.)

This process enabled the research team at EDAC to co-produce an internal set of **best practice guidelines for conducting brain imaging research with Autistic individuals with eating disorders** on any future research projects aligned with our network.

1. **The underpinning ethos and research rationale for using brain imaging should be clear and transparent from the beginning of the study.** Brain imaging approaches used with Autistic populations should be aimed at understanding Autistic brains, not to '*fix*'. However, an approach aligned with intervention may be appropriate within an ED specific focus and how to balance these opposing demands needs to be considered and shared.

2. **The research aims, questions and outcomes should be clear and transparent from the beginning of the study**. The research team should make it clear why they are doing the research and how it will help the community.

3. If you are planning on entering anonymized data into an **open science database, the research team should communicate this clearly** with the participant, using appropriate communication methods, and give them time to process what this means.

4. **Research should be conducted within a neurodiverse-affirming framework using aligned language**. For example, comparing Autistic people with an ED to Autistic people without an ED, as opposed to including neurotypical participants as a control group to explore Autistic "*deficits*" or "*dysfunction*". The aim of such research should be of benefit to the Autistic and ED community e.g., to inform ED treatment and care.

5. **Be aware that the process of brain imaging may be distressing and have the appropriate resources in place to support an individual before, during and after a study**. Discuss with your co-production team what these resources could be.

6. **Clearly communicate about what the study process will involve and what to expec**t. If possible, include study visits or videos of the room and scanner before the day of the study. Share an example of the noise with participants beforehand and encourage the use of appropriate ear plugs or defenders.

7. **Give people plenty of time and space for questions**. The research team should be available for questions via a range of communication means in the lead up to the process and before and after the scan on the day.

8. **If possible, give participants a copy of their brain scan**

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Eating Disorders and Autism Collaborative (EDAC) Case Example 2

Co-produced reflections on using arts-based approaches as a research methodology with Autistic individuals with eating disorders.

The second example of a methodology we will be using at EDAC is an arts-based approach called Photovoice. This uses photographs taken and selected by participants to discuss and reflect on their experiences. We used the same reflective questions within our research team to understand any potential ethical concerns associated this technique and to co-produce suggestions on how to mitigate these concerns or adapt protocols. The research team were able to identify the strengths of these approaches which were accessible and inclusive of individuals with a broad range of needs, such as those who are non-verbal or those with intellectual disabilities. However, the research team also identified several tensions with these methodologies including:

- Asking the participant to communicate their experience through arts-based approaches may unconsciously tap into a need to "produce" a finished piece of work, and lead to distress and anxiety. There could be some confusion around the difference between producing artwork, using arts methods in research and art therapy.
- The degree of interpretation from the researchers (who may be neurotypical without lived experience) and ensuring that this interpretation is aligned with its original meaning.
- If the choice of medium is too narrow (e.g., just painting) then it runs the risk of being exclusive; if the choice of mediums is too broad (e.g., painting, clay, drawing) then it could be overwhelming and lead to decision paralysis.
- Sensory sensitivities to certain mediums (e.g., clay)

- If the focus of the research is too narrow and there are too many prompts then it could limit creativity and expression; if the focus is too broad and without prompts, them it could become overwhelming and lead to decision paralysis.
- Protection of anonymity, especially if any pieces go on to be used to disseminate the research.

Specific to Photovoice:
- Potentially triggering images if shared with others in the community.
- Different creative styles mean that some Autistic people may feel that they can't express themselves via images and instead prefer to write creative or reflective blogs or short stories.
- Asking participants to document their experiences may lead to over analysis and overdocumentation of eating behaviours, leading to distress and anxiety.

This process enabled the research team at EDAC to co-produce a set of internal best practice guidelines for conducting ethical arts-based approaches for any future research conducted with our network:

1. **Be clear about the research purpose and intended outcome**s. Communicate what the process will involve in as much detail as possible, using different mean to support this communication.

2. **Allow enough time for participants to familiarize themselves with the mediums**. Do this before starting the study, perhaps offering some practical introductory sessions. Also have flexibility regarding the number of sessions, allowing participants to extend their numbers of sessions if needed.

3. **Communicate clearly about how you are going to protect anonymity and ownership before you start the research.** Communicate with the community about what strategies you will use to protect anonymity and ensure art and images are used only for specified outcomes (and not sold for profit etc.).

4. **Plan and conduct regularly check ins – before, during and after the research.** Ask participants before you start the study what mediums they would like to use (if possible), or any they may struggle with. Ask if there are any adaptations that you can make to accommodate for this.

5. **Distinguish between the use of artwork to support dissemination and the research itself.** People should have different consent processes for participation and dissemination and a range of options to protect anonymity.

6. **Have a safeguarding procedure in place t**hat has been discussed and agreed with the research team based on the specific needs of your population. This should involve monitoring distress throughout the process and support resources shared before and after the study.

3. Sharing Research

This final section of the guidelines will outline the last stage of the research process, disseminating or sharing research. Key challenges with this process surround how to make sure research is accessible and can be clearly understood by those that it intends to benefit - the Autistic and ED community. A high proportion of research is either communicated in highly technical language or via academic dissemination routes that are not accessible for all (e.g., in journals that the public have to pay to read or at expensive academic conferences). The following reflective points are designed to support research teams in thinking about how to engage and work together with Autistic individuals with eating disorders to make sure research findings are shared, understood and are accessible to the community.

Reflective Points for the research team to consider when sharing research.

- **How do we ensure any events sharing research are run with Autistic people with lived/living experience of an ED?** How can we ensure that these activities are mutually beneficial e.g., how do we both disseminate our research and hear feedback to support further research directions?
- **How can we make sure our research is shared with Autistic people with EDs, their network and support services?** How can we begin to foster relationships and networks that will support this? Who should we be engaging with that will make sure this research is available and accessible to the community? Are we being proactive in engaging not just with other research terms and universities, but also with clinical and community support services, schools, policy advisors, the media and other platforms? And have we considered collaborating with other organizations to develop a shared, free resource?
- **Have we made sure that those who have participated in the research have been informed of the results before the findings are shared with the community?** Have you made sure that you have a way of communicating the results with participants before your research is more broadly shared, and has this been agreed from the outset? Have we made sure that this also includes all members of the research team and that we have co-produced the summary of results before sharing with the community?
- **Have we considered the communication needs of the specific Autistic and ED community that this research is aligned with?** How can we communicate our research findings in a range of mediums and formats that will support these needs? This could include layperson written summaries, conferences, podcasts, videos, online webinars, visual boards or infographics, storyboards and engaging with social media platforms. Are we co-producing these outputs with Autistic and ED community?

- **What in person or online events or platforms would allow for meaningful sharing of research with the Autistic and ED community that this research is aligned with?** Have you asked which platforms may be preferred, or given the community enough time to familiarize themselves with the platforms?
- **Have we made sure that we are not only sharing the results from your study but, importantly, what they mean?** Are we communicating the implications of our research clearly and how they can help to improve the lives of Autistic people with an ED?
- **Have we made sure, to the best of our ability, that our research is open and free to access?**
- **Have we considered and discussed ownership of content after sharing?** Are we making sure that the principles of co-production are adhered to when sharing content? For example, the content can be co-produced but often it is the research team who post on their websites or social media platforms. Have you discussed this as a research team and made sure that everyone has given their informed consent? And does this consent include the option to change your mind - to remove a video or picture of an individual from a website, despite initially agreeing to do this?
- **Have you considered researchers', participants' and community wellbeing in your dissemination plan**? Have you thought about support resources for all involved in the sharing of research? Have you asked yourself how you would feel if this piece of research had been done on you, and how you would feel about the implications of your findings?

Important caveats to the guidelines

These guidelines have been developed for and by Autistic people with an ED and should not be transferred to other communities or groups that are not specific to the current context. Additionally, please also be aware that even within the Autistic and ED community, experiences can be very different, and it is therefore important to draw on these guidelines as a framework and not concrete rules – consult your co-production research team

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Appendix 1: Process of the workshops

Organizing the workshops. In line with EDAC's ethos – research by Autistic people with EDs, for Autistic people with EDs – we organized five workshops with around 20 Autistic people with lived/living experience of an ED. At the heart of these workshops was the need to understand what the potential barriers and facilitators are to co-producing ethical and meaningful research with this community.

We started by advertising for the workshops on social media and through stakeholders. This involved posting flyers about the role on EDAC's social media, as well as posts on Scottish Autism and SWAN's website pages. Interested participants got in touch with us, and a member of the research team met with them to discuss the process, make sure interested parties were eligible for the workshops, and to address any questions. Importantly, this was also to introduce potential participants to a member of the research team so there would be some familiarity at the start of the workshops. This was felt to be important to reduce anxiety and to increase transparency about the workshops as much as possible. Pictures of the project leads and our peer researcher were also posted on the recruitment flyers too.

Once all 20 Autistic people with lived/living experience of an ED had been confirmed for the workshops, a detailed timeline of the workshops were shared, including dates, times and topics of the workshops. The workshops were run online and were run every two weeks. For the first workshop, an agenda and meeting invite was sent two weeks in advance to give people plenty of time to familiarize themselves with the information and the new platforms. Between workshops, there was also scope to use an online discussion forum for 'offline' thoughts and discussion using a website called Padlet. There was a new Padlet board for each week, and this included the weekly content, any videos that were going to be shared during the workshop, and space to post comments. Those taking part were encouraged to post any thoughts or comments in the lead up to the workshop, as well as after the workshop in case they did not have the time to share or were unable to share during the 'live' discussions. A research team member also posted key discussion points after the workshops, and the link to the Padlet remained live for all workshops. In line with discussions from peer researchers, we designed the workshops to have these multiple communication formats to make the process as accessible and inclusive as possible. While this was decided before the workshops started, we also checked in with participants halfway through the process to make sure that these formats were working for all.

Running the workshops. 5 workshops were run between December 2023 and February 2024. In the first session, several group terms and principles were proposed and discussed, and the agreed version was posted on the Workshop 1 Padlet board as a reminder throughout the

workshops. This was an important part of the process, establishing group terms and principles from the beginning whilst also ensuring this was a collaborative process.

The remaining workshops then focused on discussing different aspects of the co-production process. We started by discussing general concerns in autism and ED research, as well as early concerns about potential barriers to engaging in co-produced autism and ED research. Across the next three workshops, we conducted a 'deep dive' into specific aspects of the research process, focusing on how to ethically design, conduct and disseminate co-produced research. The final two workshops focused on co-produced the current guidelines, presenting drafts and reviewing the document until we reached a whole group agreement on the following contents.

Appendix 2: Best Practice Guideline Handouts (www.edacresearch.co.uk)

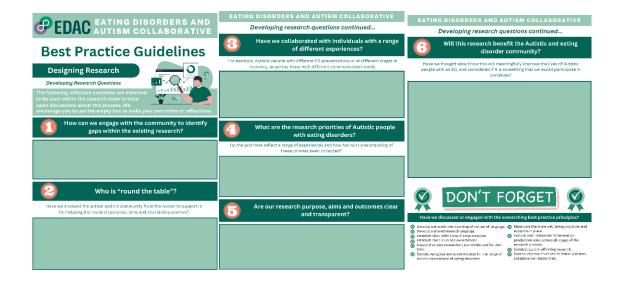### *Complete Best Practice Guidelines Handouts*

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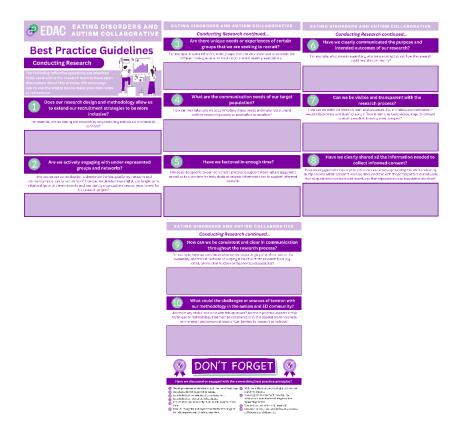
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