



# Eating Disorders and Autism Collaborative

A UK wide collaborative network bridging the gap between autism and eating disorders research



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[www.edacresearch.co.uk](http://www.edacresearch.co.uk)



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Bridging the gap between autism  
& eating disorder research.

Barriers and Facilitators to ethical co-production with Autistic individuals with lived/living experience of eating disorders

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# Autism and Eating Disorders

- 20-30% of individuals with anorexia nervosa display autism characteristics (Westwood, et al., 2017).
- Individuals who report more autistic features present more severe ED symptoms (Kerr- Gaffney et al., 2019) are more likely to require inpatient treatment of NG feeding (Stewart et al., 2018) and report poorer global outcome post treatment (Neilsen et al., 2022)
- Disordered eating is widely reported in autistic individuals but reliable estimates of the prevalence of EDs are scarce
- Concerns have been raised about the effectiveness and potential harm of traditional ED treatments for autistic population (Babb, et al., 2021)
- ED clinicians have expressed a lack of confidence in treating individuals with co-occurring autism and AN (Kinnaird et al., 2017)

# Becky Choat: Scottish Women's Autism Network (SWAN)

“I feel excited to be representing SWAN in partnership with EDAC as for me the importance of understanding the relationship between autism and eating disorders is clear. My own frustrations at society's lack of understanding about autistic relationships with food, sensory experiences, trauma and social pressures that are only then magnified by inaccessible services have been echoed by so many in the autistic community and many attempts to slightly adapt existing neurotypical approaches and services from an outside-in perspective have just been a sticking plaster without an informed consideration of autistic lived experience.”

# Overarching Aim and Objective

Aim: To increase research innovation and capacity in the field of ED's

Objectives:

- 1) Supporting interdisciplinary collaboration across the ED and autism field
- 2) Supporting development of interdisciplinary networks bringing together academia, third sector, policy, clinicians and Autistic individuals with lived experience of ED's
- 3) Ensure that networking, priority setting and research activity is led and directed by Autistic individuals with lived experience of an ED
- 4) Capacity building and career development via ECR and peer researchers
- 5) Unique Scottish research collaboration

Collaborative workshops exploring the ethical challenges and best practice approaches of research for Autistic People with lived experience of eating disorders.

2023



**WS1: Coming Together**

**WS2: Setting the Agenda**



Use Photovoice to allow Autistic individuals with eating disorders to share their experience and set priorities for research.

Interdisciplinary sandpit events to extend existing networks and tackle priorities identified in workstream 2.



**WS3: Testing the Approach**

**WS4: Knowledge Mobilisation**



Think tank event for policy makers and those working in clinical practice.

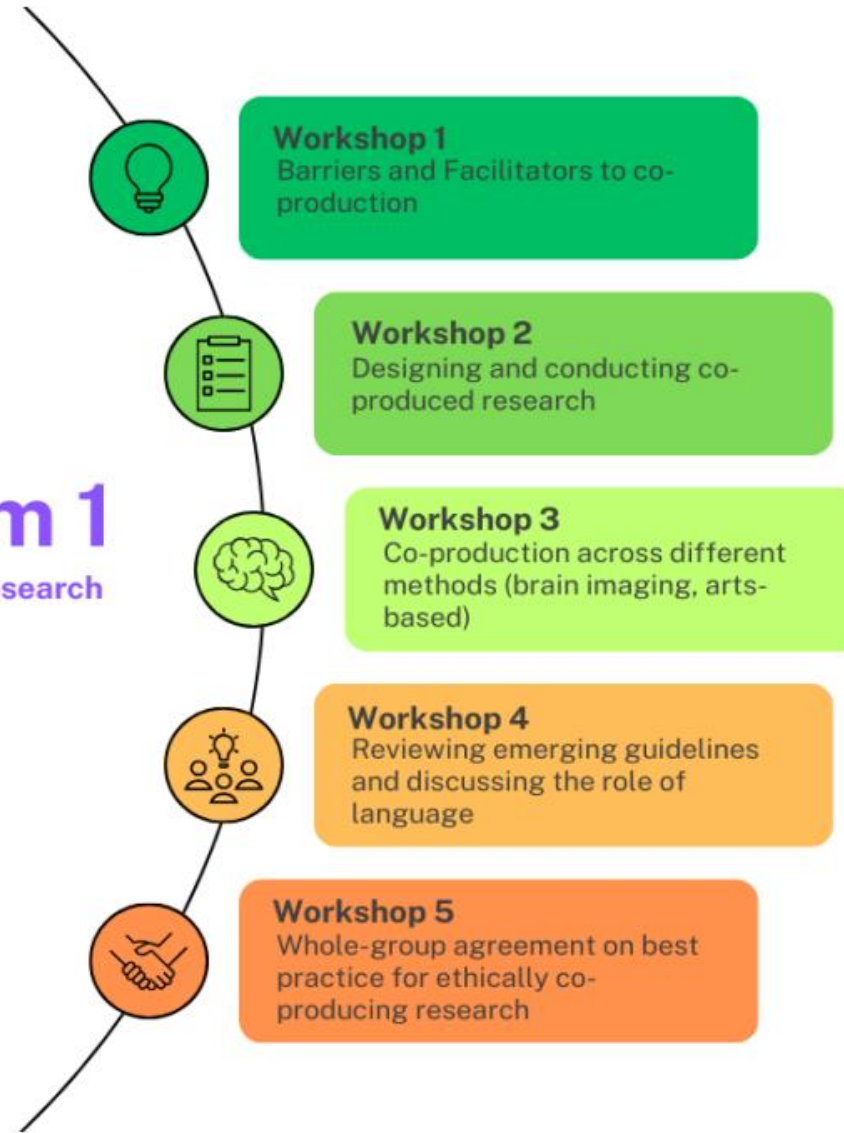
2025

# Workstream 1

- 5 workshops with around 20 Autistic people with lived/living experience of an ED, clinicians and researchers (acknowledging some individuals had multiple identity/roles)
- Advertised on social media and through stakeholders (Scottish Autism and SWAN)
- Participants were paid for their time and workshops ran fortnightly.
- Communication and processing time was supported via multiple platforms to support individual needs e.g. padlet before and after workshops, uploading videos of content ahead of time, chat functions, reminder emails, one point of contact in research team, option for on-to-ones

# Workstream 1

How to ethically co-produce research





# Best Practice Guidelines for Conducting Ethical Co-produced Research with and for Autistic Individuals with Eating Disorders

*“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.”*

*EDAC, 2024*

1. **Getting Started** highlighting potential barriers to developing co-produced research.
2. **Key Principles for Ethical Co-Production** to address historical research concerns & barriers to co-production.
3. **Reflective questions** to support a research team in **Designing Research**, focusing on identifying research questions and how to navigate tensions surrounding what we are measuring and how we are measuring it.
4. **Tools** for open discussions on **Conducting Research**, with a focus on recruitment
5. **Disseminating Research** - reflective points to consider sharing accessible research findings

# Co-Production

Refers to researchers and community members working together as equal partners from the beginning of the research process.

## Benefits of Co-Production in autism and eating disorder research

- It enables the community who are going to be most affected by the research to shape it – it is the morally right thing to do: “***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 as created mistrust in the Autistic community. Co-production has capacity to build trust in the research team.
- Empowers members of the community to be involved in research, learn new research skills and take an active part in academia
- Provides essential and valuable new insights to the research team, alongside challenging preconceptions, and stigma.

# Barriers to Co-production

## Barriers for the Autistic and ED community:

- Researchers being tokenistic or engaging in '*faux production*', '*Dropping in*' on communities
- Lack of autism knowledge amongst research groups, leading to feelings of being misunderstood
- Autistic people with EDs feeling they show such different presentations of EDs that they may not fulfill researcher expectations
- The distressing or potentially triggering nature of taking part.
- Researchers only engaging with people they find it '*easy*' to communicate with and lack of adaptations to communication.
- The co-production role is only advertised after the topic has been decided on, often by neurotypical people.
- Lack of trust in researchers after negative experiences including stigma, and dehumanizing language from researchers

## Barriers for researchers:

- Lack of clear guidance and support for what co-production involves
- Time and getting funding to compensate those with lived experience for their time
- Concerns about "*getting it wrong*"

## Barriers for both :

- Lack of clear definitions of what co-production is
- Speaking different languages between researchers and lived experience leading to a '*language barrier*'.
- Unrealistic expectations for both, what individuals supporting co-production 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.

# Best Practice Principles

1. **Develop a shared understanding of the use of language.** Discuss and agree on acceptable language
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.
3. **Establish clear definitions of co-production.**
4. **Establish clear roles and expectations.**
5. **Ensure that peer researchers are reimbursed for their time.**
6. **Recognize and accommodate communication differences.**
7. **Make sure there are wellbeing practices and support in place** for the co-production team.
8. **Involve peer researchers in several co-production roles across all stages of the research process**, including design and leadership roles.
9. **Conduct autism-affirming 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.

# Reflective questions

 **EDAC** EATING DISORDERS AND AUTISM COLLABORATIVE

## Best Practice Guidelines

### Designing Research

*Developing Research Questions*

The following reflective questions are intended to be used within the research team to have open discussions about this process. We encourage you to use the empty box to make your own notes or reflections.



**1** How can we engage with the community to identify gaps within the existing research?

**2** Who is “round the table”?

Have we involved the autism and ED community from the outset to support in formulating the research purpose, aims and intended outcomes?

EATING DISORDERS AND AUTISM COLLABORATIVE

*Developing research questions continued...*

**3** Have we collaborated with individuals with a range of different experiences?

For example, Autistic people with different ED presentations or at different stages in recovery, as well as those with different communication needs.

**4** What are the research priorities of Autistic people with eating disorders?

Do the priorities reflect a range of experiences and how has our understanding of these priorities been collected?

**5** Are our research purpose, aims and outcomes clear and transparent?

EATING DISORDERS AND AUTISM COLLABORATIVE

*Developing research questions continued...*

**6** Will this research benefit the Autistic and eating disorder community?

Have we thought about how this will meaningfully improve the lives of Autistic people with an ED, and considered if it is something that we would participate in ourselves?

 **DON'T FORGET** 

Have we discussed or engaged with the overarching best practice principles?

- Develop a shared understanding of the use of language.
- Develop a shared research language.
- Establish clear definitions of co-production.
- Establish clear roles and expectations.
- Ensure that peer researchers are reimbursed for their time.
- Recognise and accommodate communication differences.
- Make sure there are well-being practices and supports in place.
- Involve peer researcher in several co-production roles across all stages of the research process.
- Conduct neurodiverse-affirming research.
- Seek to improve trust and to foster a shared, collaborative relationship.

## Best Practice Guidelines

### Conducting Research

The following reflective questions are intended to be used within the research team to have open discussions about this process. We encourage you to use the empty box to make your own notes or reflections.



**1** Does our research design and methodology lend itself to extending our recruitment strategies to be more inclusive?

For example, are we biasing our research by only recruiting individuals in clinical ED services?

**2** 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?

EATING DISORDERS AND AUTISM COLLABORATIVE

*Conducting Research continued...*

**3** 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.

## Best Practice Guidelines

### Conducting Research

The following reflective questions are intended to be used within the research team to have open discussions about this process. We encourage you to use the empty box to make your own notes or reflections.



**1** How do we ensure any sharing of research events are run with Autistic people with eating disorders?

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?

**2** How can we make sure our research is shared with Autistic people with eating disorders, their network and support services?

Have we engaged with a range of sectors and stakeholders to make sure the research is available and accessible?

EATING DISORDERS AND AUTISM COLLABORATIVE

*Conducting Research continued...*

**3** 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 we made sure that we have a way of communicating the results with participants before our research is more broadly shared, and has this been agreed from the outset?

# Scottish Women's Autism Network

- “To partner with EDAC and see the way they authentically work in collaboration from the beginning, taking time to listen and develop shared understanding at every stage has generated such a positive response from those already involved and hopefully go on to drive a much greater autistic-led understanding of eating disorders. ”
- Becky Choat, SWAN



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## CONTACT US



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