Eating Disorders and Autism Collaborative

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

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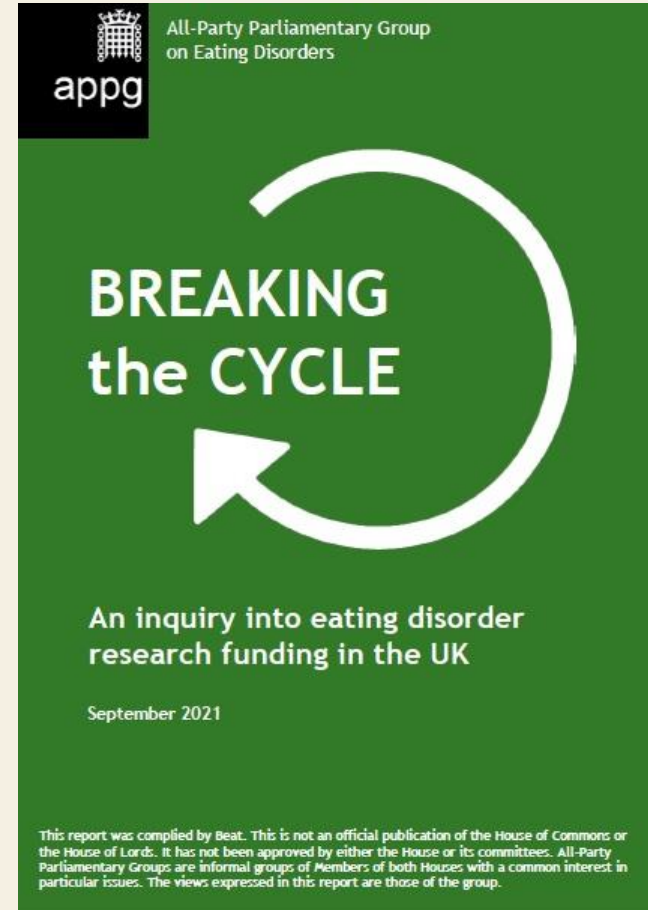
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Bridging the gap between autism & eating disorder research.

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New collaborations call to support eating disorders research

- Funding Call September 2022 via combined pot from UKRI, MRF and NIHR.

- Total fund £4250000

- Aims to address APPG report "vicious cycle of underfunding" report on UK ED research

- Funding to support novel collaborations in ED research

- Want to increase capacity in the field by funding collaborations across disciplines and fields adjacent to or not previously involved in ED research

- Focus on research representing under-represented groups and driven by PWLE

All-Party Parliamentary Group on Eating Disorders

appg

BREAKING the CYCLE

An inquiry into eating disorder research funding in the UK

September 2021

This report was compiled by Beat. This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either the House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

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

WS2: Setting the Agenda

WS4: Knowledge Mobilisation

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

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

2023

2025

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

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

WS1: Coming Together

WS3: Testing the Approach

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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

Workshop 1
Barriers and Facilitators to co-production

Workshop 2
Designing and conducting co-produced research

Workshop 3
Co-production across different methods (brain imaging, arts-based)

Workshop 4
Reviewing emerging guidelines and discussing the role of language

Workshop 5
Whole-group agreement on best practice for ethically co-producing research
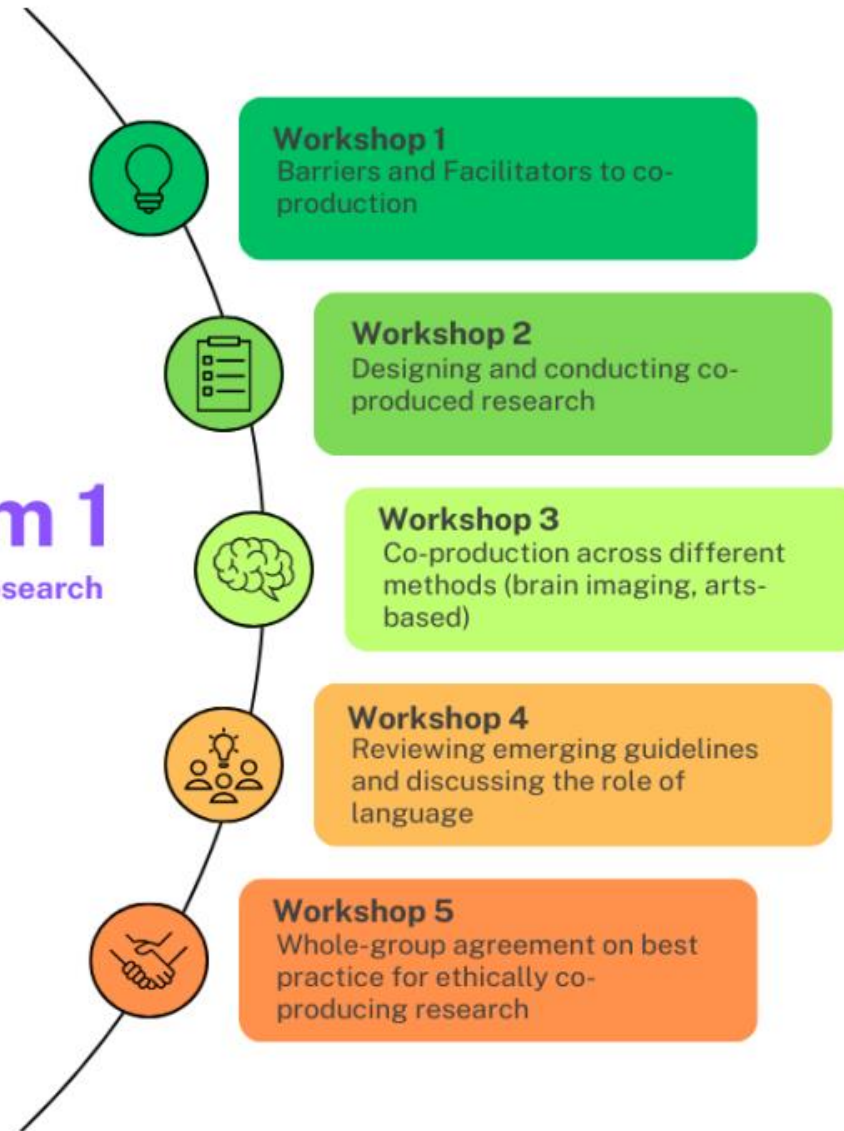
Best Practice Guidelines for Conducting Ethical Co-produced Research with and for Autistic Individuals with Eating Disorders

"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.

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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

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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?

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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 priories been collected?

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

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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.

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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?

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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.

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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?

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Workstream 2:

Setting the Agenda

Setting the Agenda: Arts-based Priority Setting Event – Autistic group

- Setting the Agenda workshop with PWLE with LD and their parents:

- Photovoice will be used with n = 40 Autistic people who have ED – emphasis on recruiting under-represented groups including men, LGBTQ+, BAME and all ED presentations e.g. OFSED, BED etc. to explore common and distinct priority themes.

- The format of these sessions will include 5 sessions which will be supplemented by scoping and systematic reviews of the literature by the funded research assistant. The priority setting activity will be carried out based on the James Lind Alliance framework (https://www.jla.nihr.ac.uk/jla-guidebook/).

- As part of these sessions sensory interviews will be carried out by Autistic people asking their peers about sensory experiences of food and of the setting priorities task.

Setting the Agenda: Arts-based Priority Setting Event – group with Intellectual Disabilities

- Setting the Agenda workshop with PWLE with LD and their parents:

- Photovoice will be used with both the PWLE with LD (n = 15) and their parents and/or carers (n = 15) to explore experiences and establish common and distinct priority themes.

- The format of these sessions will include 5 sessions which will be supplemented by scoping and systematic reviews of the literature by the funded research assistant. The priority setting activity will be carried out based on the James Lind Alliance framework (https://www.jla.nihr.ac.uk/jla-guidebook/).

- As part of these sessions sensory interviews will be carried out asking PWLE with ID and their parents and carers about their experiences of setting priorities

Workshops

Workshop	Purpose	
1	Trust building. Discuss research purposes and Photovoice. Discussion of Photovoice process. Camera training. **Homework:** To do 1st assignment – 'What is your experience of eating disordered behaviour?'	Reflections Of research and ethics (ID Only).
2	Discuss photos/drawings. Peer feedback. **Homework:** To do 2nd assignment – 'What are the research priorities for Autistic People who have lived experience of Eating Disorders?'	
3	Discuss photos/drawings. Peer feedback. **Homework:** Reflect and take additional images of priorities/experiences.	
4	Provide general themes from 1st and 2nd assignment to the group and obtain feedback.	
5	Present refined themes and priorities back to the group and get feedback.	

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Timeline

Tasks and Work Streams	2024		
	Feb-Apr (6-9 months)	May-July (9-12 months)	Aug-Oct (12-15 months)
Work Stream 2.1: Setting the Agenda (Autism, SK)			
Photovoice ethics application for n=40			
Refine photovoice protocols (using approaches from co-production guidance from workstream 1)			
Recruitment			
Photovoice sessions			
Output: interviews co-produced with PWLE (including video interviews of process)			
Output: priority setting reports/article			
Output: online and in-person exhibition of photovoice images and art (e.g., teaser of Photovoice for EDAW 2024)			
Work Stream 2.2. Setting the Agenda (ID, KGS)			
Photovoice ethics application for n=15 ID and n=15 parents			
Refine photovoice protocols (using approaches from co-production guidance from workstream 1)			
Recruitment			
Photovoice sessions			
Output: interviews co-produced with PWLE (including video interviews of process)			
Output: priority setting reports/article			
Output: online and in-person exhibition of photovoice images and art			