

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?

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?

Developing research questions continued...



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.
- » Recruit, recognize and accommodate for the range of Autistic experiences of eating disorders.
- » 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 autism-affirming research.
- » Seek to improve trust and to foster a shared, collaborative relationship.

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Designing Research

What and How to Measure?



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

What are the measurement 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 in research and creating unnecessary barriers to participation?

2

Are our measures meeting the needs of our population?

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?

What and How to Measure continued...

3

Are there opportunities to explore individual symptoms, experiences and underpinning mechanisms?

Would this approach be more aligned with the communities' research priorities?

4

If our research design requires specific approaches that create tension with the communities needs or priorities (e.g. formal diagnosis, recruitment approaches, randomisation), how can we acknowledge this as a potential limitation and be transparent about why?



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Best Practice Guidelines

Conducting Research



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1

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?

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?

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.

4

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?

5

Have we factored in enough time?

This could be specific to our recruitment process to support meaningful engagement, as well as to allow time for individuals to process information and to support informed consent.

Conducting Research continued...

6

Have we clearly communicated the purpose and intended outcomes of our research?

For example: what we are researching, why we are doing this and how the research could help the community?

7

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?

8

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?

Conducting Research continued...

9

How can we be consistent and clear in communication throughout the research process?

For example, have we considered whether we have a single point of contact, or the availability of different methods of keeping in touch with the research team (e.g., email, online, chat function or face-to-face discussions)?

10

What could the challenges or sources of tension with our methodology in the autism 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?



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Best Practice Guidelines

Sharing 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?

Sharing 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?

4

Have we considered the communication needs of the specific autism and eating disorder 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?

5

What in person or online events or platforms would allow for meaningful sharing of research with the autism and eating disorder community that this research is aligned with?

Sharing Research continued...

6

Have we made sure that we are not only sharing the results from the study but, importantly, what they mean?

Are we communicating the implications of your research clearly and how they can help to improve the lives of Autistic people with an ED?

7

Have we made sure, to the best of our ability, that the research is open and free to access?



8

Have we considered and discussed ownership of content after sharing?

Have we discussed this as a research team and made sure that everyone has given their informed consent? 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?

Sharing Research continued...

9

Have we considered researchers', participants' and community well-being in your dissemination plan?

Have we thought about support resources for all involved in the sharing of research? Have we asked ourselves how we would feel if this piece of research had been done on us, and how we would feel about the implications of our findings?



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