

Best Practice Guidelines

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?



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.