

Inclusive Autism Research Participation Framework

Background

We have drawn from our insights of the research process, the ELPART, and focus group interviews, an inclusive autism research participation framework. **Please note this framework was developed mainly with parent/carers of autistic children. The next steps to further developing this framework are to co-develop further the framework with ethnically diverse autistic individuals.** This is not a ticklist that must be adhered to but aspects to consider. Please use the website [anto](#) to support the points below.

The framework aims to promote inclusive recruitment for your projects, community-focused recruitment is essential and involves collaborating with various community groups. The framework helps researchers to think about how to meaningfully embrace cultural context, empathy, and reflective practice.

Some terminology

Experts by Experience (EbEs) are individuals who have lived through a particular situation or condition and uses that use their personal experience to inform research, policy, or practice.

A **collaborative partner** is an individual or organisation that actively works together with others on a shared project or goal. In research or community work, this means co-designing, co-delivering, and co-evaluating activities or studies. Collaborative partners, these may include community faith-based organisations, voluntary charity organisations, councils or the NHS.

Community-Centred Recruitment

- Partner with collaborative partners, these may include community leaders and faith-based organisations but recognise that not everyone accesses these or may not engage in these spaces. Therefore, also explore other avenues such as voluntary charity organisations and the NHS.
- Involve Experts by Experience (EbEs) from similar cultural backgrounds who also have experience with autism throughout the project.
- Agree on a shared philosophy and approach to co-production (e.g., the [ELPART](#)).

Safe and Culturally Sensitive Spaces

- Where possible, use EbEs and/or researchers that reflect the community's cultural and/or religious background or are empathetic to their experiences around autism.

- The research team should understand how autism is spoken about in a community and how this may differ from the academic or other contexts.
- Collectively research team and individually researchers should authentically engage in their biases and make space and time to explore these throughout the research project by reflective practice.
- When discussing the cultural background of participants and/or EbEs take an active listening approach with a non-judgmental mindset.
- Have clear boundaries on roles, which are clearly articulated in ethics applications and to the research team.
- Build in time to support EbEs and research teams to debrief and develop their skills.

Flexible and Accessible Communication

- If needed, build funding for translation of research materials into community languages.
- Use plain language and provide culturally relevant examples of outward-facing communication.
- Provide multiple formats/options for communication (written, verbal, visual).
- Anticipate differences in language and/or approaches used to describe work with EbEs, research methodologies, and project outcomes when collaborating with multi-disciplinary teams from various sectors (e.g., NHS, Voluntary Charity Organisations and Universities). Clarify and agree on differences and common ground (e.g., vision, aims, terminology)
- Understand and put in place an approach to support different working styles which are common in neurodiverse teams.

Plan sustainable project outcomes and impact.

- Understand which research methods work better for the communities you are working with.
- Encourage diverse ways of presenting outcomes (e.g. storytelling via creative methods and/or use of different technologies and spaces).
- Create possibilities for ongoing connections within researched community participants, EbEs and/or project team (e.g., community-led events, further projects) and avoid [helicopter research](#).
- Show how to link to policy, practice, services, or future research.
- Provide updates and opportunities for continued involvement.
- Share outcomes in accessible and engaging formats.

Empowerment Through Participation

- Allowing space for participants, EbEs and the research team to share and reflect on their learning journey during the research process.
- Acknowledge participants and EbEs as co-creators, not just data sources.
- Understand that sharing stories is emotional and/or joyous; support may be needed. Be clear who will do this and how.

Inclusive Design and Ethics

- Use co-design and participatory action research approaches.
- Respect confidentiality, especially in tight-knit communities.
- Ensure ethical sensitivity and informed consent.
- Ensure payment is appropriate and that universities have a system set up.

Expect the unexpected

- Participatory approaches are not always linear. Be adaptable, resilient, and flexible within ethical guidelines.
- Build in time for the unexpected.
- Identify who can help with unexpected challenges and share these challenges so other researchers know they are not alone!
- Understand that different organisations have different operational structures which may not align with your own.
- Expect participatory research to be a fantastic opportunity to gain experience, deepen your own reflective practices (we are lifelong learners), and be inspired!