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## Shaping Autism Research in the UK

We know that there is a gulf between the autism research that gets done and the research that people in the autism community want. In the 2013 report, [A future made together: shaping autism research in the UK](#), Liz Pellicano, Adam Dinsmore and Tony Charman categorised funded autism research projects and published academic papers, and contrasted this with perspectives of the autistic community. Only a small proportion of research focused on the topics that mattered most to people such as:

- evaluating autism practice
- improving public services
- developing an understanding of autism in society.

The [Shaping Autism Research](#) seminar series has been developed to try and address this problem. Liz Pellicano drew together a group of researchers from across the UK<sup>1</sup> who all shared a desire to improve the match between the research that gets done, and the research that people want.

Over six seminars, in 4 cities across the UK, autistic and non-autistic people who were researchers, practitioners, community leaders, parents and study participants, got together to discuss these issues. Autistic leadership and visibility was high, though these were not fully autistic-led events. The seminars were designed around three topics - practice, public services, autism in society - but in the end we mostly talked about *how* and *why* research should be done, rather than *what* questions needed answering.

This shift in the discussion was probably the most exciting development for me because of the way it opens up, rather than shutting down, fields of exploration. For example, autistic people have said that they want more research into their sensory experiences. But if those sensory experiences are underpinned by fundamental differences in the action of neurochemicals in the

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<sup>1</sup> The series was created and led by Liz Pellicano, Tony Charman, Sue Fletcher-Watson, Sue Leekam, Damian Milton and Jeremy Parr. Peter Beresford provided early input to the series development. Additional co-hosts from the autism community at each seminar included Kabie Brook, Cos Michael, Joe Powell, and Lynda Morgan.

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brain, then a study on the basic biology of sensory neurons might be more aligned with community priorities than it seems at first glance.

The seminar series showed me that we don't need to rule out whole swathes of enquiry: what is important is that the work is participatory. This means that the question is identified, the methods developed, and the data interpreted and shared in collaboration with autistic people and their allies. This is a deeply positive message that emphasises a community of practice working together, rather than sorting academic disciplines into good and bad categories.

### **A participatory research model**

So, how do we go about building the community of practice we need to deliver these participatory methods? Some basics are already well known – for example, the importance of using respectful language to talk about autism and the need to create an enabling environment in which autistic people can contribute. Our series went beyond these basics, and [identified five topics which are essential parts of developing a more participatory and collaborative research model](#) in which autistic academics and autistic people in the community lead and / or partner in research projects.

#### Respect

Respecting autistic people as equal partners, taking their voices seriously and allowing them to be heard. This also works in the opposite direction: non-autistic academics need reassurance that their research training and the constraints on their work will also be respected.

#### Authenticity

Avoiding tokenistic involvement by working with autistic people who are skilled, invested in, and/or knowledgeable about the specific topic being studied. Authenticity also requires that collaborators recognise and attempt to address imbalances of power, such as those that exist between academic and non-academic partners, and between autistic and non-autistic people within academia.

#### Assumptions

Effective collaboration requires people to let go of their assumptions about what autistic people are capable of, or about what biases they might bring to the process. Researcher should recognise their own biases and allow autistic people to challenge these. This topic also included discussion of how to better include non-speaking autistic people.

#### Infrastructure

Here we identified and called for changes to the research infrastructure, where this acts as a barrier to participatory working. Such barriers include lack of funding and effective payment systems for collaborators outside academia, and the need for more effective mentoring of autistic academics during their PhDs and beyond.

#### Empathy

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This topic draws on Damian Milton's [double empathy problem framework](#), emphasising the need for people with diverse experiences and perspectives to work to find common language and shared goals. Building trusting relationships is key.

In the future we'd like to see more supportive environments in place for participatory working in autism research. There are methodological challenges ahead - such as how to deal with issues where there is a real absence of consensus, and how to draw out the perspectives of autistic people with learning disabilities, or who struggle to communicate their beliefs. The best way to tackle these challenges is collectively.

We believe that meaningful participation in autism research can help us make a better future for autistic people, together.

## References

Fletcher-Watson, S., et al. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism*, <https://doi.org/10.1177/1362361318786721>