

## Title: Opening up Understanding of Neurodiversity: A Call for Applying Participatory and Open Scholarship Practices

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### The dilemma of representation in neurodiversity research

Recent movements towards a more open, intersectional, and inclusive academia (Birhane & Guest, 2020) focus on the need to address traditional power imbalances detrimentally affecting under-represented individuals (e.g., women: Pownall & Rogers, 2021; people of colour: Berhe et al., 2022; non-WEIRD [Western, Educated, Industrialised, Rich, and Democratic] societies: Puithllam et al., 2022). Hitherto, neurodivergent perspectives —i.e. non-pathological variations in human brains (Walker, 2021)— are often overlooked and misunderstood within behavioural and cognitive sciences. It is common to encounter assumptions that anything outside of neurotypicality is at best dismissed as outlier data, or at worst, considered disadvantageous and in need of ‘fixing’ (e.g., Gernsbacher & Pripas-Kapit, 2012). Such viewpoints hinder a broader understanding of human behaviour and cognition. Here, we call for more **open** and **Participatory Research** on neurodiversity through addressing the issue of **power imbalance**.

### Neurodiverse perspectives can lead to a more representative science

Neurodivergent individuals (e.g. autistic, dyslexics, dyspraxics...) are often considered objects of study rather than active research contributors, leading to erroneous and harmful assumptions about them (Elsherif et al., 2022). A proposed solution is the adoption of Participatory Research practices, defined as incorporating the views of neurodivergent individuals and their allies into the whole research cycle, from project design to dissemination and application of findings (Bourke, 2009; Fletcher-Watson et al., 2021). Participatory

Research can potentially a) challenge general existing assumptions (i.e., neurodivergence is inferior to neurotypicality); b) promote neurodivergent individuals as **active** collaborators in research, as opposed to **passive, tokenised** objects (Elsherif et al., 2022; Pellicano & den Houting, 2022); c) reduce bias in theories and interpretations of human cognition and behaviour by drawing inspiration from neurodivergent individuals' lived experiences and strengths (e.g., creativity: Pellicano & den Houting, 2022; Sedgwick et al., 2019); and d) promote recruitment of neurodivergent individuals from more diverse socio-demographic backgrounds and cognitive or adaptive (dis)abilities. Through these mechanisms, Participatory Research practices have the potential to improve scientific rigour and credibility (MacFarlane & Chang 2008; Yeung, 2022), strengthen generalisability, and promote social justice in behavioural and cognitive sciences.

### **Open Scholarship & Participatory Research: an essential combination to advance neurodiversity research**

We propose that Participatory Research alongside Open Scholarship can increase representation of neurodiverse individuals, improve generalisability, and research practices. Open Scholarship is defined as the creation, dissemination, consumption, and application of knowledge through adhering to the principles of transparency, reproducibility, credibility and integrity, alongside inclusion and social justice (e.g., Pownall et al., 2022). Both Open Scholarship and Participatory Research share integral values that enable meaningful contributions to the scientific community and society at large (e.g., improving accessibility within academia and society; Azevedo et al., 2022; Parsons et al., 2022).

These approaches can be coupled with “Big Team Science” (e.g., Tierney et al., 2020, 2021) to empower and support neurodivergent researchers in contributing to research itself. This allows neurodivergent researchers to focus on specific steps according to their individual strengths (e.g., intense focus and rigour allows detailed comments to improve study design; Hawker, 2017). As a group of both neurodivergent and neurotypical academics ourselves, we have experienced this Big Team Science approach as enabling our views to be integrated.

Anchoring Participatory Research to Open Scholarship practices will promote wider epistemic justice, and enable equality in knowledge production. Additionally, this will result in the development of knowledge that represents the communities it describes. For example, while Big Team Science projects have tested research questions with very large and more geographically diverse samples, we are unaware of any such project designed in collaboration with communities. The epistemic views powered by and powering the Big Team Science approach still largely represent privileged and well-funded institutions in the Global North, therefore perpetuating existing power imbalances in knowledge production (Puthillam et al., 2022).

More recent Open Scholarship initiatives including [ABRIR](#) (Advancing Big-team Reproducible science through Increased Representation, 2022) and [FORRT](#) (Framework for Open and Reproducible Research Training; Azevedo et al., 2019) have arisen to enable projects designed by a more diverse community of researchers. However, a further step towards epistemic justice is to empower lay communities to become research contributors, reducing knowledge gatekeeping by academics. In neurodiversity research, we argue for not only involving neurodivergent researchers, but also integrating views of wider neurodivergent communities from projects' outset, including when seeking funding, so that the participation of community members can be rewarded appropriately in addition to being recognized through CRediT (Allen et al., 2014).

Despite the potential benefits of combining Participatory Research and Open Scholarship movements, some challenges must be considered. Firstly, there is a need for more Open Scholarship resources in neurodiversity research and education, including further training and resources (e.g. Pownall et al., 2021). Secondly, for Participatory Research to shine, there needs to be mutual trust, and a shared vision for inclusive communication, fair compensation, and the barriers that need to be overcome. This can be achieved, for example, by asking community members to serve on advisory boards for projects relevant to that community (see Jilka, 2021 for applications in mental health research), and consulting this board at each design stage, including in reviewing funding applications and manuscripts (Elsherif et al.,

2022). Subsequently, we believe that Open Scholarship can provide: a) a blueprint of specific opportunities to encourage participation of diverse researchers and communities; b) guidance for concrete practices to acknowledge Participatory Research appropriately (e.g., CRediT system; Allen et al., 2014) and disseminate findings collaboratively (e.g., Open Educational Resources). These necessary steps in turn would reduce power imbalances and allow neurodivergent individuals to feel empowered.

## Conclusion

We argue for combining Participatory Research and Open Scholarship practices as an essential way to advance neurodiversity research. This combination can have manifold benefits: it can strengthen the relationship between members of the public and scientific communities, empower neurodivergent people, and ensure current research is meaningful and impactful to their lives. Eventually, combining participatory and Open Scholarship practices can be a pathway to more **open, robust, diverse, and inclusive** science.

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