

## **Meaningful research for Autistic people? Ask Autistics!**

Rebecca Poulsen<sup>1,2,3</sup>, Charlotte Brownlow<sup>1,4</sup>, Wenn Lawson<sup>1,5</sup>, & Elizabeth Pellicano<sup>1,5</sup>

<sup>1</sup>Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia; <sup>2</sup>Queensland Brain Institute, University of Queensland, St Lucia, Queensland, Australia; <sup>3</sup>Reframing Autism, Sydney, Australia; <sup>4</sup>Centre for Health Research, University of Southern Queensland, Toowoomba, Queensland, Australia; <sup>5</sup>Macquarie School of Education, Macquarie University, Sydney, New South Wales, Australia.

Word count: 1,266 words

The last decade has witnessed the emergence of a powerful call from Autistic people to have real input into the decisions that shape their lives. This participatory approach underpins discussions regarding autistic involvement with issues from social policy, human rights, justice, and accessibility rights, through to meaningful and effective approaches to clinical, medical, therapeutic, and educational practices. The heart of the message is, in part, about acceptance: embracing and valuing autism as part of the human spectrum. It is also about ensuring that meaningful change can be driven by those who have a true and deep understanding of the strengths and needs from their own experiential expertise.

The slogan that best captures this idea -- "*nothing about us without us*" -- rings especially true within the world of research, with implications for both *what* research is done and *how* it is conducted. Autism researchers have responded across the world. There is a deepening recognition that having rigorous methodological design that is participatory in nature improves the outcomes of research (den Houting et al., 2021; Fletcher-Watson et al., 2019; Gillespie-Lynch et al., 2017; Nicolaidis et al., 2019; Pellicano, 2020; Pellicano et al., 2021). Additionally, there is a growing appreciation that participation helps researchers to translate their ideas more effectively into recommendations for concrete change in clinical or educational practice or broader public policy (Adams et al., 2018; Benevides et al., 2020; Gillespie-Lynch et al., 2021; Leadbitter et al., 2021; Shattuck et al., 2018; Warner et al., 2019).

It is indisputable, therefore, that participatory research is gaining momentum among autism researchers. It remains, however, far from the dominant approach. In practice, much autism research continues to exclude autistic input except in the capacity of a research participant (Fletcher-Watson et al., 2019; Milton & Bracher, 2013; Milton et al., 2019) and those few studies that include Autistic people in the decisions around research, are all too often tokenistic in nature (den Houting et al., 2021). Indeed, as Milton (2019) argues, Autistic people have traditionally been viewed as the subjects on which research is conducted rather than cast in the role of researcher.

To try to capture this reality, recent investigations in different countries have sought to compare the interests of Autistic people themselves with the interests of autism researchers

(e.g., Benevides et al., 2020; Cusack & Sterry, 2016; Frazier et al., 2018; Pellicano et al., 2014). In Australia, this has led to a recent publication of a report by the Australian Autism Research Council (AARC), a group of community members from different stakeholder groups, including Autistic people, parents and carers and researchers, which sits under the auspices of the Cooperative Research Centre for Living with Autism (Australian Autism Research Council, 2021a). The AARC seeks to understand the research priorities of the Autistic and autism communities. It derived its answers in the most straightforward way: by directly asking Autistics and related community members to reflect on the kind of research that they wanted to see prioritised (Australian Autism Research Council, 2021a).

For the past three years, the AARC has collaborated with the Autistic and autism communities to better understand and identify their priorities for research. In 2019, more than 1,000 community members helped identify ten broad research priority areas to improve understanding of the diverse experiences, preferences, and needs of communities across the autism spectrum and lifespan. In 2021, the AARC sought to delve deeper into five of the areas, including communication, education, employment, health and wellbeing, and justice, to identify more fine-grained research questions.

In so doing, a diverse range of Autistic people, parents, carers and family members of autistic children or adults and professionals with relevant expertise were recruited into the working groups for each of the five priority areas with a small number of 'priority perspectives' proactively included for each. For example, the Communication priority working group included Autistic people who communicate through non-traditional means, Autistic people and family members who had experienced challenges due to a lack of communication supports, Autistic people from non-English speaking backgrounds and professionals working in relevant fields. In-depth discussions and consultation yielded ten research questions for each of the five areas (Australian Autism Research Council, 2021b). Across these research priority areas, there are clear thematic undercurrents – which, in hindsight, are unsurprising. First, the topics are almost exclusively focused on improving understanding of the diverse experiences, preferences, and needs of Autistic people, while also developing knowledge, understanding, and approaches to

inform policy, practices, and supports. Second, the priorities identified often reflect the importance of training and development, particularly for professionals – rather than Autistic people themselves – while creating opportunities to increase awareness and understanding about the Autistic community. Finally, there is a call for widespread change in societal attitudes, to promote a broader view of the capabilities of members of the Autistic community, thus replacing representations that pathologize and marginalise individuals.

Now that the research priorities have been identified and we have a clear steer from community members regarding the ways in which autism should be understood and responded to within research (see also Cascio et al., 2020; Pellicano, 2020), the task now is to understand further how new research partnerships can practically facilitate inclusive research design and participatory research in the longer run. In the United Kingdom, the Participatory Autism Research Collective (PARC) seeks to bring together academics, activists, and practitioners to facilitate greater involvement of Autistic people in autism research (see Milton et al., 2019). The AARC report is similarly designed to act as a launch pad for researchers, providing essential insight into relevant research questions, but also discusses the important question of *how* research should be conducted around these topics. The consultation clearly identified that Autistic people and their allies want to be involved in research decision making – from research design, through to the dissemination of the research itself, thus creating a true participatory environment. Research, programs, and policies must be about Autistic people, and be led and co-produced with people from the Autistic and autism communities. Doing so effectively can take more time than traditional research (Brett et al., 2014; Fletcher-Watson et al., 2019). But its rewards are manifold, including ensuring that research reflects the real needs of the community (Cascio et al., 2020; Chown et al., 2017; Cusack & Sterry, 2016; Jivraj et al., 2014).

The people involved in the AARC's consultation also wanted to see a shift in the way that autism is fundamentally approached analytically – that is, from an excessively narrow, deficits-based view of autism to one which sees autism as a form of variation within a diversity of minds (Adams et al., 2018; Pellicano & den Houting, 2021; Raymaker, 2016). This latter neurodiversity framework stresses the need to view Autistic people as unique and worthwhile individuals,

whose lives have meaning and purpose, and urges us to look beyond the individual, focusing on how Autistic people might flourish within a range of contexts. It can also help promote Autistic people's agency in making decisions about their own lives. Shifting the focus of research to what the community considers important will significantly improve Autistic people's experiences of society through widespread acceptance and inclusion.

The AARC report points us in the right direction, with research questions pinpointed within each of these prioritised areas, reflecting the needs of the Autistic and autism communities, and ensuring that the gaze of new research has an appropriate focus. The community's voice is clear: addressing these research priorities will not only help build a true understanding of Autistic people and the broader autism community, but will in turn shape policy, practices, and research funding in such a way as to promote Autistic flourishing.

### **Acknowledgements**

All authors are members of the Australian Autism Research Council, which operates under the auspices of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program. We are grateful to ORIMA research, especially Tamara Reinisch and Gabrielle Hall, for their work on the recent community consultation; all of the community members who so generously gave up their time to take part in that consultation; all of the AARC members for their continued commitment to meaningful autism research; Melanie Heyworth and Emma Goodall for their insights and expertise; and Tori Haar, Marc Stears, Julie Lounds Taylor and Aubyn Stahmer for their support and comments on a previous draft of this editorial.

## References

- Adams, D., Heussler, H., & Gray, K. (2018). Behavioural phenotypes: working towards translational research through research partnerships. *Journal of Intellectual Disability Research : JIDR*, 62 8, 661-663. <https://doi.org/10.1111/jir.12513>
- Australian Autism Research Council (2021a). *2020-21 Research Priority Update*. [https://www.autismcrc.com.au/sites/default/files/aarc/AARC\\_2020-21\\_Research\\_Priority\\_Update.pdf](https://www.autismcrc.com.au/sites/default/files/aarc/AARC_2020-21_Research_Priority_Update.pdf)
- Australian Autism Research Council (2021b). *Research report on focus groups to identify research questions for community informed priority areas: Final report*. [https://www.autismcrc.com.au/sites/default/files/aarc/AARC\\_Research\\_Report\\_Focus\\_Groups\\_Final\\_Report.pdf](https://www.autismcrc.com.au/sites/default/files/aarc/AARC_Research_Report_Focus_Groups_Final_Report.pdf)
- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24, 822-833. <https://doi.org/10.1177/1362361320908410>
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*, 17, 637–650.
- Cascio, M. A., Weiss, J. A., & Racine, E. (2020). Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism*, 24(7), 1676-1690. <https://doi.org/10.1177/1362361320918763>
- Chown, N., Robinson, J. A., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability & Society*, 32, 720-734. <https://doi.org/10.1080/09687599.2017.1320273>
- Cusack, J., & Sterry, R. (2016). *Your Questions: Shaping Future Autism Research*. London: *Autistica*.

den Houting, J., Higgins, J., Isaacs, K. B., Mahony, J., & Pellicano, E. (2021). 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*, 25, 148-163. <https://doi.org/10.1177/1362361320951696>

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23, 943-953. <https://doi.org/10.1177/1362361318786721>

Frazier, T. W., Dawson, G., Murray, D., Shih, A., Sachs, J. S., & Geiger, A. (2018). Brief Report: A Survey of Autism Research Priorities Across a Diverse Community of Stakeholders. *Journal of Autism and Developmental Disorders*, 48, 3965-3971. <https://doi.org/10.1007/s10803-018-3642-6>

Gillespie-Lynch, K., Bisson, J. B., Saade, S., Obeid, R., Kofner, B., Harrison, A. J., Daou, N., Tricarico, N., Delos Santos, J., Pinkava, W., & Jordan, A. (2021). If you want to develop an effective autism training, ask autistic students to help you. *Autism*, 13623613211041006. <https://doi.org/10.1177/13623613211041006>

Gillespie-Lynch, K., Kapp, S., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology*, 8. <https://doi.org/10.3389/fpsyg.2017.00438>

Jivraj, J., Sacrey, L.-A. R., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18, 782-793. <https://doi.org/10.1177/1362361314539858>

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice. *Frontiers in Psychology*, 12, 635690. <https://doi.org/10.3389/fpsyg.2021.635690>

Milton, D., & Bracher, M. (2013). Autistics speak but are they heard. *Medical Sociology Online*, 7, 61-69.

- Milton, D., Ridout, S., Kourti, M., Loomes, G., & Martin, N. (2019). A critical reflection on the development of the Participatory Autism Research Collective (PARC). *Tizard Learning Disability Review*. <https://doi.org/https://doi.org/10.1108/TLDR-09-2018-0029>
- Nicolaidis, C., Raymaker, D. M., Kapp, S., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23, 2007-2019. <https://doi.org/10.1177/1362361319830523>
- Pellicano, E. (2020). Commentary: Broadening the research remit of participatory methods in autism science - a commentary on Happé and Frith (2020). *Journal of Child Psychology and Psychiatry*, 61, 233-235. <https://doi.org/10.1111/jcpp.13212>
- Pellicano, E., & den Houting, J. (2021). Annual Research Review: Shifting from “normal science” to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, in press.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18, 756-770. <https://doi.org/10.1177/1362361314529627>
- Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Heyworth, M., Clapham, H., & Yudell, M. (2021). “I knew she’d get it, and get me”: Participants’ perspectives of a participatory autism research project. *Autism in Adulthood*, in press.
- Raymaker, D. M. (2016). Intersections of Critical Systems Thinking and Community Based Participatory Research: A Learning Organization Example with the Autistic Community. *Systemic Practice and Action Research*, 29, 405-423. <https://doi.org/10.1007/S11213-016-9376-5>
- Shattuck, P. T., Lau, L., Anderson, K. A., & Kuo, A. (2018). A National Research Agenda for the Transition of Youth With Autism. *Pediatrics*, 141, S355-S361. <https://doi.org/10.1542/peds.2016-4300M>
- Warner, G., Parr, J. R., & Cusack, J. (2019). Workshop Report: Establishing Priority Research Areas to Improve the Physical Health and Well-Being of Autistic Adults and Older People. *Autism in Adulthood*, 1, 20-26. <https://doi.org/10.1089/aut.2018.0003>

