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Opening up autism research: Bringing open research methods to our field

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Participating in autism research costs autistic people time and energy. Participants give that time in the hope of supporting researchers to generate new evidence and insights that could help autistic people to enjoy happier and healthier lives. A key element of translating research into this kind of meaningful impact is that findings are reliable and that the process for arriving at them is clear. Open research is a system for producing a reliable evidence base by facilitating greater transparency and robustness in research practices (Munafò et al., 2017). It draws on a wide toolkit of different methods and techniques that aim to open up the research process from start to finish. They include preregistering study protocols and hypotheses, making research methods and materials freely available, and publishing study data so it is accessible to others.

If deployed correctly, open research methods could help us achieve our collective goal to make a positive difference in the lives of autistic people. New forms of support offered to autistic people must be built on a robust evidence base, one in which findings can be translated to practice with confidence. Indicators of robustness include power, replicability and transparency. Power means that studies have large enough samples to detect important effects, reducing the chance of false positives. The literature must include publication of null results from well-powered studies, otherwise publication bias towards significant differences skews the evidence base. Replicability allows estimates of effect size to be reproduced reliably across studies, so true and not-true effects can be differentiated. This helps to ensure that significant findings are not false positives arising from questionable research practices such as flexibility in how data were collected and analysed (Simmons et al., 2011). Transparency means that the field has mechanisms of preventing grey research practices, such as a p-hacking (running an inappropriate number of tests on one's data, without suitable hypotheses for doing so) and 'HARKing' ('hypothesising after results are known', where researchers retro-fit hypotheses to predict statistically significant results). These recommendations extend to both applied research and more basic research that illuminates theories about autism. Open research methods should expedite the potential impact of autism research by generating confidence in findings. However, there are challenges autism researchers will face in adopting these methods.

First, autism researchers will need access to suitable training in open research methods. Lack of training is a frequently reported barrier to the uptake of open research practices (Gownaris et al., 2022). Open research approaches may also take additional time and resources, and these too will need to be made available for open research in autism to be viable. Fortunately, there is an increasing appetite and interest in open research. Major funding bodies (e.g. UKRI, 2021) support and even expect open research practices in the research that they fund. Indeed, the field of autism would be wise to embrace these methods, as researchers may soon find that they are expected to take them up in order to obtain funding.

A second consideration is that not all open research approaches are suitable for all forms of research. Autism research spans a wide range of fields and topics, and some methods may be better suited to some questions than others. Specifically, we must be careful that enthusiastic adoption of open research methods does not inadvertently exclude qualitative research. Open research remains largely the territory of the quantitative researcher, especially those working with frameworks that seek to formulate and test hypotheses. But qualitative research has much to offer autism research, and we should be wary of suggesting such research is of a 'lower quality' because its adoption of open research looks different, or has necessarily been taken up at a slower pace (Haven et al., 2020; Kern & Gleditsch, 2017). That said, there are aspects of qualitative research that can be made open. There are some examples of pre-registration of qualitative studies (e.g. Karhulahti et al., 2021; Spitzer & Mueller, 2021). While it may be impossible to share raw data without compromising participant anonymity, researchers' coding frameworks or reflexive diaries can be made open to make the decision making behind the analysis transparent. Indeed, the UK data sharing service has produced a detailed set of guidelines for anonymising and depositing qualitative datasets, as well as ensuring safeguarding of sensitive data by allowing researchers to set criteria for access on a project-by-project basis.¹

In adopting open research methods, we also need to consider the importance of progressive theoretical work and avoid *methodolatry*, whereby employing more 'rigorous' methodological standards is taken as a panacea for all

of the problems in a field of research. Indeed, we cannot move to a model in which all research is confirmatory, testing established hypotheses via pre-registered techniques. Scholars in wider psychological science have argued that psychology lacks good theory and that the application of hypothesis testing frameworks is hollow when the theories behind some hypotheses are weak or indeed absent altogether (Eronen, & Bringmann, 2021; Scheel et al., 2021). In autism research, theoretical models are far from universally supported (Fletcher-Watson & Happé, 2019), and we still need exploratory work that generates new hypotheses for future testing.

Other challenges relate to trust. We know that many in the autistic community are dissatisfied by the failure of research to deliver concrete improvements in their lives (Pellicano et al., 2014) and some are distrustful of researchers' intentions (Gowen et al., 2019; Milton, 2014). On the face of it, adopting open research methods should improve trust between autistic people and autism researchers, as these approaches shine a light into all aspects of the research process. For example, a pre-registered protocol and analysis plan provides a clear statement of the purpose of a piece of research, unaffected by the pattern of results.

However, there are also aspects of open research methods that could cause concern among many autistic people. In particular, data sharing may alarm a community that has been historically disenfranchised from autism research (Botha, 2021; Chapman & Carel, 2022). This is exacerbated by the fact that many important forms of data for autism research, such as video footage of assessments, is very risky to share openly – and indeed may be actively prevented by legislation in some parts of the world (e.g. the General Data Protection Regulation in the European Union). As well as worries about breaches of confidentiality, there is also the possibility that data contributed for one purpose are subsequently re-used by another researcher for purposes less aligned with the participant's own priorities. Thus, any attempt to open autism research must prioritise developing and maintaining trust of participants and stakeholders. Community consultation on practices such as open data sharing and autistic people's attitudes towards open research methods in general would be very valuable.

Another concern is what could happen to autistic people as a result of tasks and materials made openly available. To some extent, some freely available autism-related measures, such as the Autism Quotient (Baron-Cohen et al., 2001), are open research success stories. Yet such openness also means that people can complete measures without guidance from clinicians or researchers. Self-insight generated from access to these measures can be a very powerful tool and a step towards accessing a diagnosis. However, the delinking of self-report measures from professional guidance can be distressing if people infer from the results that they are 'impaired' in some way. This

may be especially the case for experimental tasks or new questionnaire measures where we may have very little insight into how non-autistic people perform.

The concept of 'epistemic injustice' is important when considering the challenges described above. This is the act of privileging some sources of knowledge over others – for example, minimising the importance of knowledge gained from lived experience. Currently, the quantitative, biomedical disciplines with most established open research practices are also those with the least participatory input from autistic people (Pellicano, 2020). Epistemic injustice in autism research could lead to quantitative, researcher-led and pre-registered research with published data gaining higher status than qualitative, community-led, necessarily closed research. A clear understanding of the differences between exploratory and confirmatory research, and a celebration of both as vital parts of autism research, is essential.

What are the next steps for open autism research? Wider discussion with the autistic community will be important to the success of these practices in our field. Such discussions will need to take place carefully: we do not want to imply to our key stakeholders that research that is not open is inherently flawed, as this will risk further loss of trust in research by the autism community. We hope to see wider adoption of open research practices in autism research in future, including registered reports and pre-registration. These are powerful tools to present researchers' hypotheses and research aims upfront and thereby reduce researcher bias. We should also consider what good stewardship of autism research data looks like; how can we share research data in a way that makes maximum use of the time and energy that autistic people and their families have spent giving it to us, while ensuring it is used in line with the wishes of the participants, in a manner that is safe and respectful? By integrating open research principles into autism research, while ensuring these methods adhere to over-arching values which centre autistic flourishing, we can create a stronger evidence base to support autistic people to thrive.

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1. <https://ukdataservice.ac.uk/learning-hub/qualitative-data/>.

References

- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, *31*(1), 5–17.
- Botha, M. (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. *Frontiers in Psychology*, *12*, 727542.
- Chapman, R., & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy*. Advance online publication. <https://doi.org/10.1111/josp.12456>.
- Eronen, M. I., & Bringmann, L. F. (2021). The theory crisis in psychology: How to move forward. *Perspectives on Psychological Science*, *16*(4), 779–788.
- Fletcher-Watson, S., & Happé, F. (2019). *Autism: A new introduction to psychological theory and current debate*. Routledge.
- Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2019). Guidelines for conducting research studies with the autism community. *Autism Policy & Practice*, *2*(1), 29.
- Gownaris, N. J., Vermeir, K., Bittner, M. I., Gunawardena, L., Kaur-Ghumaan, S., Lepenies, R., Ntsefong, G. N., & Zakari, I. S. (2022). Barriers to full participation in the open science life cycle among early career researchers. *Data Science Journal*, *21*(1), 2.
- Haven, T. L., Errington, T. M., Gleditsch, K. S., van Grootel, L., Jacobs, A. M., Kern, F. G., Piñeiro, R., Rosenblatt, F., & Morkink, L. B. (2020). Preregistering qualitative research: A Delphi study. *International Journal of Qualitative Methods*, *19*, 1–13. <https://doi.org/10.1177/1609406920976417>
- Karhulahti, V. M., Siuttila, M., Vahlo, J., & Koskimaa, R. (2021). Phenomenological strands for gaming disorder and esports play: A qualitative registered report. *PsyArXiv*. Advance online publication. <https://doi.org/10.31234/osf.io/q53jz>
- Kern, F. G., & Gleditsch, K. S. (2017, May 23–24). *Exploring pre-registration and pre-analysis plans for qualitative inference* [Paper presentation]. From Transparency to Replication in Qualitative Inference: Guidelines and Tools, Colchester, UK. <https://www.researchgate.net/publication/319141144>
- Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, *18*(7), 794–802.
- Munafò, M. R., Nosek, B. A., Bishop, D. V., Button, K. S., Chambers, C. D., Percie du Sert, N., Simonsohn, U., Wagenmakers, E.-J., Ware, J. J., & Ioannidis, J. (2017). A manifesto for reproducible science. *Nature Human Behaviour*, *1*(1), 0021.
- 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*(3), 233–235.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756–770. <https://doi.org/10.1177/1362361314529627>
- Scheel, A. M., Tiokhin, L., Isager, P. M., & Lakens, D. (2021). Why hypothesis testers should spend less time testing hypotheses. *Perspectives on Psychological Science*, *16*(4), 744–755.
- Simmons, J. P., Nelson, L. D., & Simonsohn, U. (2011). False-positive psychology: Undisclosed flexibility in data collection and analysis allows presenting anything as significant. *Psychological Science*, *22*(11), 1359–1366.
- Spitzer, L., & Mueller, S. (2021). Registered Report Protocol: Survey on attitudes and experiences regarding preregistration in psychological research. *PLoS One*, *16*(7), e0253950.
- UKRI. (2021). Open research. <https://www.ukri.org/what-we-offer/supporting-healthy-research-and-innovation-culture/open-research/>

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