Autism Research Publication Style Sheet & FAQ: Community-Preferred Language

This was prepared for and by members of the AIMS-2-TRIALS consortium including researchers and Autism Representatives with input from the Autism Research Centre. This document reflects the views of the research and autism community that have been part of this process.

AIMS-2-TRIALS prioritises maintaining the working relationships between AIMS-2-TRIALS researchers and autistic collaborators, as well as the broader autism community. As such, this document has been created to detail for editors of scientific publications the rationale behind language choices that have been made in papers submitted by AIMS-2-TRIALS researchers based on feedback from the autism community. We hope it will serve as a useful supporting document for journal submissions that will aid editors during the process of publication and help everyone avoid potential misunderstandings. When creating summaries or editing an AIMS-2-TRIALS paper for publication, we respectfully request that these choices be honoured as much as is feasible. For further information or clarification, please contact either the paper's author or communication@aims-2-trials.eu.

Terms to limit	Preferred Term	Notes
normal, healthy, typical	**non-autistic**	This language avoids the implication that non-autistic people are somehow more 'normal' than autistic people - and avoids any value judgments.
ASD, Autism Spectrum Disorder	***In order of preference*:** 1. **Autism** 2. **ASC / Autism Spectrum Conditions**	ASC can be used in place of ASD (Autism Spectrum Disorder) - the use of the term 'disorder' implies that there is something inherently wrong and undesirable about being autistic. Many offensive people have explicitly stated that they find disorder-related language offensive and upsetting. **With that in mind, using the word, 'autism' is preferable whenever possible**, as 'conditions' still has medicalised connotations that are not always applicable to autistic lives.
person/people with autism	**Autistic person / people**	In general, multiple studies in the past decade have shown autistic people prefer identity-first language. Default to this unless referring to an individual who has stated a specific preference otherwise.
risk (of autism)	**Increased likelihood, increased chance**	'Risk,' much like the more obviously negative word 'danger,' implies that whatever you are about to describe is inherently negative and to be avoided. On the other hand, 'likelihood' or 'chance' is value neutral. If a condition is universally accepted as negative (e.g. epilepsy) the use of 'risk' is appropriate.
high/low functioning	**high/low support needs**	The vast majority of autistic people need some form of support at some point, and this can vary between people and across a person's life. Stating this idea is not offensive. On the other hand, 'high/low functioning' is first a fixed and global state: once labelled as such, that label is perceived to apply across all aspects of life in perpetuity , regardless of circumstances. Second, it is often inaccurate: some autistic people have persistently high support needs in an area of their life, e.g. communication, but are extremely independent when those structures are put in place effectively. Still others may vary between high and low support needs over the course of years, months, or even over the course of their day.
personalised / targeted medicine, personalised/ targeted interventions	**personalised / targeted support**	'Support' covers options that go beyond merely pharmacological treatments, which helps open up thinking around autistic needs; also, 'support' is free of the medicalised context of other terminology (implying that autism is a disease needing a cure)
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Other medicalised terminology, e.g.: patient, comorbidities	*Neutral terminology, e.g.*: **Participant, co-occurring conditions**	Unless a study participant was referred to a study because they were a patient, it is inaccurate to refer to them as a patient. Many autistic people are physically healthy and not patients under care. When referring specifically to autistic people with co-occurring conditions that create a need for medical care, such as epilepsy or rare genetic conditions that create health complications, medical terminology may be appropriate.
challenging behaviour, disruptive behaviour, problem behaviour	**meltdown; shutdown; stimming; soothing**	Behaviour is simply a reaction to stimuli. While a behaviour might result in harm, it is not the autistic person's intention to be challenging, disruptive, or problematic - these behaviours serve a purpose and can have value. Describing the behaviour itself rather than an external perception of the behaviour provides more context into what is being communicated, and also sets aside the potential impact on non-autistic onlookers in order to prioritise autistic needs over non-autistic comfort.
stratification, subtyping	subgrouping	Many autistic people realise that autism can look very different from person to person and can involve a variety of co-occurring conditions that often benefit from interventions. Because of this, there is community support for research into subgroup-specific diagnostics and support. On the other hand, the lack of real understanding of what autism actually is makes subtyping on the basis of observable differences a futile effort, and sometimes includes language that implies that one subtype is superior to another, or suggests a kind of hierarchy (e.g. stratification) which is offensive and connects back to the origins of autism research in eugenics. **If talking about subgrouping, be clear about the rationale and purposes, so that your audience is not left to make assumptions.**
Deficit-based terminology or generalisations, e.g: empathy "gap", deficient, deficiencies (especially when discussing subjective issues, such as social and/or emotional), 'Participant cannot…'; 'participant struggles with…'	*Strengths-based terminology, e.g.:* **autistic skills, 'Strong in _____, needs support in _____', 'Participant is not yet able to…' 'Participant sometimes / occasionally struggles with'**	Strengths-based terminology asks people involved in autistic support, research, and advocacy to lead with the strengths of autistic people. Strengths-based approaches have been used in other academic spheres to support positive outcomes among marginalised groups to great success - in the field of biomedical research, they can be a way to approach and formulate questions about autism and autistic people's outcomes without bringing ableist ideas of 'curing autistic traits' into the picture. Strengths-based approaches take the agency and humanity of autistic people as a given, rather than looking at autism as, at its core, a deficit to be remedied.
Special needs	**Support needs (or preferably describing a specific support)**	The use of the word 'special' is likely to be experienced as patronising, like something an adult might tell a small child; additionally, the needs an autistic person has should not carry the connotation that they are extraordinary or burdensome, which is implied in 'special.'
Abnormal, etc. (any language which implies value)	**neurodivergent**	This is a blanket term describing any person/people who are not neurotypical - **generally it is preferable to use the specific term (autistic, ADHD, dyslexic, dyspraxic, etc.) being discussed** unless multiple terms apply and are relevant. [Note: there are still disagreements within the autism community, often between autistic adults and parents/carers of autistic people with high support needs, about the meaning, usage, and relevance of this term. As mentioned above, when interacting with an individual, use terminology preferred by the individual.]

Frequently Asked Questions

If autism is still listed in diagnostic guides such as the DSM-V as Autism Spectrum Disorder, why shouldn't we refer to it in that way?

Professional bodies like the Royal College of Psychiatrists increasingly recognise the value that discussing autism as a neuropsychiatric condition rather than a disorder has in supporting autistic mental health and have begun doing so in College-authored work, just as they recognise the harm that is caused by the stigmatising language and framing of autism as inherently a disorder.[1] If a researcher has used the term 'autism' or 'ASC' in place of ASD, it is a deliberate choice in light of community preferences and we recommend this is retained in edits.

Why is there a problem with the use of 'patients' vs 'healthy controls' when it is common in other papers outside of the field of autism research?

There are two issues: accuracy and implications. First, unlike in other subfields of biomedical research, it is extremely common for research participants to come to a study on autism research through pathways other than clinical referrals, so calling them 'patients' and calling control groups 'healthy controls' is simply an inaccurate mischaracterisation of the groups being studied. Second, these terms are explicitly related to need for medical care. Use of the terms in autism research implies that autism is a medical condition and autistic people are inherently less healthy. This idea is untrue, and it adds to the stigma.

We have a policy of using person-first language when it comes to autism because it puts the personhood first. Why are you using something different?

Although this is still a matter of individual preference, studies since 2016[2] surveying the broader English-speaking autism community on these descriptors have repeatedly shown[3] a strong preference[4] for identity first language ('autistic person') among autistic people, who see person-first language as contributing to the stigma around autism.[5] This contrasts with attitudes of parents/family members, which showed a preference for person-first language in earlier studies that has decreased or disappeared in more recent surveys, and attitudes of non-autistic clinicians, educators, and support workers in the field of autism, who are split in their preference. Preferred terminology changes as understandings shift, and it makes the most sense to follow the preferences of the people whose experiences are being described.

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[1] Davidson, C., Carpenter, P., & Mohan, R. (2022). Autistic psychiatrists: Royal College of Psychiatrists response. The British Journal of Psychiatry, 221(3), 582-582. doi:10.1192/bjp.2022.84

[2] Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. Autism, 20, 442–462. https://doi.org/10.1177/1362361315588200

[3] Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. Autism. 2023 Feb;27(2):565-570. doi: 10.1177/13623613221130845. Epub 2022 Oct 13. PMID: 36237135.

[4] Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. Autism Research, 16(2), 406–428. https://doi.org/10.1002/aur.2864

[5] Bury, S. M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D., & Spoor, J. R. (2022). Understanding language preference: Autism knowledge, experience of stigma and autism identity. Autism, 0(0).