

# GUIDELINES FOR AUTISM-FRIENDLY SELF-QUESTIONNAIRES

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## Respect

- Instead of applying a deficit approach, be non-judgemental and respectful. Avoid pejorative or stigmatising descriptions that have connotations to experiences/traits being abnormal/unusual, such as “disorder” or “impaired”.
- Use gender-inclusive language to actively address everyone with your words.
- Do not use stereotypes.
- Consider and accept language preferences of the community, such as identity-first (autistic person), instead of person-first language (person with autism. Another largely acceptable option is people on the autism spectrum (cf. Kenny, Hattersley, Molins, Buckley, Povey, and Pellicano, 2016; Keating, Lydia Hickman, Joan Leung, Ruth Monk, Alicia Montgomery, Hannah Heath, Sophie Sowden, 2023).
- Differentiate between behaviour towards allistic and towards (other) autistic individuals. For instance, autistic individuals might be misunderstood by non-autistic interlocutors but not necessarily by other autistic individuals.

One of our collaborators commented:

*“It is important to differentiate between social interactions with allistic/neurotypical people and with other autistic individuals, and sometimes with other neurodivergent people as well, as the latter is usually easier for autistic individuals. Communication difficulties depend heavily on the environment. The representation of social situations as a problem for autistic individuals in questionnaires refers to interactions with allistic/neurotypical people, which are used as the only correct standard - this approach is ableist. It is important to consider the Double Empathy Problem.”*

(Marie Maroske)

## Accessibility

- Make sure the literal interpretation of the text matches your intended interpretation. Instead of using figurative language and metaphors, or quotation marks to indicate conditional word meanings, make everything concrete and explicit.
- Be precise, instead of using vague formulations. Imprecise language might create an obstacle for autistic individuals. For instance, “several times a day” is clearer than “often”.

One of our collaborators commented:

*“Precision = Accessibility. If this is not given, it can lead to misunderstandings, incorrect results, and great frustration and loss of energy. Sometimes, it may not even be possible to complete the questionnaire.”*

(Marie Maroske)

- Where necessary, make it broad enough (e.g., always give at least two examples) but do not generalize too much. In some cases, examples might be counterproductive as they can distract autistic individuals by restricting the relevance of the item to a particular context or scenario.
- Do not assume that people are always aware of the strategies they apply or the reasons for their behaviours.
- Guide people to consider the relevance of statements both in the present as well as across their lifetime. This would help capture persistent characteristics of respondents' disposition, as opposed to their current context.

## References

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- 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>
- 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(4),442-62. <https://doi.org/10.1177/1362361315588200>