

Open letter to the Lancet Commission on the future of care and clinical research in autism

14th February 2022

We wish to address *the Lancet Commission on the future of care and clinical research in autism* on behalf of the *Global Autistic Task Force on Autism Research*, a committee comprising autistic advocates, researchers and representatives of organisations by and for autistic people.

As the Commission emphasised the importance of collaborative participation, we look forward to being included as collaborators. We appear to have remained largely invisible, generalised briefly as ‘the neurodiversity movement’.

It is encouraging that the need for system change and the value of neurodiversity were recognised by the Commission. However, some omissions contradict this message. Studies mapping autistic people’s priorities regarding research were not mentioned. Participatory research was mentioned but not defined, nor was literature on its principles cited.

We find the proposal to adopt the term ‘profound autism’ highly problematic, as well as the overall emphasis on behavioural interventions, excluding more recent, promising approaches. We disagree with the recommendation to focus clinical research on randomised controlled trials for short-term interventions, including medication and behavioural trials.

To improve autistic lives, we need concepts developed by autistic scholars applied to clinical research. We need research on causes of mortality, access to health care, and improving mental health support. We need research on screening and diagnosis for all countries, and the health consequences of system factors: discrimination, mistreatment, poverty and lack of access to appropriate services. We need closer involvement of autistic people to ensure that clinical trials are truly ethical, and to curb the development of pseudo-treatments.

We call for shared, accessible platforms to continue the discourse and start building collaboration.

Signatories ([country codes](#) in parentheses)

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| European Council of Autistic People (EUR) | Heta Pukki (President) Martijn Dekker (Board member) |
| Autistic Self Advocacy Network (US) | |
| Collectivo Autista Mi Cerebro Atípico (INTL) | Bárbara Herrán (CEO) |
| Autistic Doctors International (INTL) | Mary Doherty (ADI Founder) Sebastian Shaw (ADI Research Lead) Sue McCowan (ADI Psychiatry Lead) |
| Participatory Autism Research Collective (UK) | Damian Milton (Chair) |
| Autismus-Forschungs-Kooperation (DE) | Silke Lipinski (for the working group) |
| Autistic Collaboration Trust (INTL) | Jorn Bettin (Chairperson) Quinn Dexter (Advisory Board Member) |

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| Lees- en Adviesgroep Volwassenen met Autisme (BE) | Jo Bervoets |
| Autism Rights Group Highland (UK) | Kabie Brook (Chairperson) Joshua Hennessy (Assistant Chairperson) |
| Asociación Autistas de Colombia (CO) | Monica Vidal Gutierrez |
| The Autistic Realm Australia Inc. (AU) | Kylieanne Derwent (Co-Founder & Vice Chair) |
| estas, Adult Autistic Self-advocacy Meeting (KR) | Yoon, wn-ho, Jang Jiyong (Co-moderators), Onemoo Lee |
| Asociația suntAutist (RO) | Ovidiu Platon (Chair) |
| Suomen Autismikirjon Yhdistys (FI) | Minna Brockmann (Chairperson) Annikka Suoninen (Project Coordinator) |
| PAS Nederland (NL) | Tammo Michel (chairperson / secretary) |
| Otoemojite (neurodiversity self-help group)(JP) | Satsuki Ayaya |
| CLE Autistes (FR) | Garance Jacquot (Secretary) for the Board |
| Autisme- og Aspergerforeningen for Voksne (DK) | Nina Catalina Michaelsen (Chairperson) Silke Rudolph (Board Member/Treasurer) |
| Inicijativa za autizam i ostale neurodivergentnosti, samozastupanje i kulturu različitosti ASK (autistic initiative)(HR) | Kosjenka Petek, Sunčica Lovrečić Čekić |
| Aspies e.V. (DE) | Hajo Seng, Rainer Döhle (Chairs) |
| Autistics Unmasked (US) | Heini Natri |
| Adventor o. s. (CZ) | Michal Roškaňuk (Chairman) |
| A-komunita (CZ) | Vojta Bartošík (Chairman) |
| Asociación Autistas de Mexico (MX) | Yadira Garcia Rojas (President) Giovanna Villarreal Estrada (Secretary) |