

Community Involvement Reporting: Frequently Asked Questions

From the *Autism* Manuscript Submission Guidelines, Section 2.8.3: Community involvement

Autism encourages research that is actively carried out ‘with’ or ‘by’ members of the Autistic and autism communities (rather than ‘to’, ‘about’, or ‘for’ them), often referred to as ‘co-production’, ‘participatory research’, ‘patient and public involvement’ or ‘integrated knowledge translation’.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the [BMJ’s editorial guidelines](#) for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

1. When and why did *Autism* start requiring community involvement statements?

Autism started requiring authors to include a community involvement statement in 2021.

Our editorial team were inspired by the example of the British Medical Journal, which requires authors submitting research papers to complete a statement documenting if and how they involved “patients and the public” in their work. This is part of an editorial strategy to promote co-production in clinical research.

Similarly, at *Autism* we value involving representatives from the autism community in the co-production of research. Autistic people’s perspectives are always valuable, and often other stakeholders such as parents of autistic people, or practitioners (teachers, therapists, doctors) will add value too. The community involvement statement in our published research articles signals our values and plays a part in increasing the use of participatory methods.

2. What is the purpose of the community involvement statement?

Requiring a community involvement statement allows us to:

- (i) signal the fact that we value community involvement and think it is an important part of autism research
- (ii) provide a dedicated space for researchers to report community involvement methods and to credit community partners (where these are not also co-authors). Reporting the methods used is an essential part of enabling autism researchers to share innovative and excellent practice.
- (iii) provide a citeable evidence base to support community involvement elements in grant applications, student project proposals and so forth.

We are proud that papers published in our journal provide a growing resource to support dissemination of community involvement practices for autism research, and beyond.

3. Is a community involvement statement needed for every type of manuscript?

No. A community involvement statement is only required for research reports, sharing new empirical findings. They will also be relevant for inclusion in Short Reports, where these are also sharing new findings.

A community involvement statement will not normally be included in a review paper, commentary or letter to the editor. However if you feel community involvement is relevant – for example, if a community member was involved in selecting inclusion criteria or interpreting the results of a systematic review – then we would always encourage you to report this.

4. What counts as “community” for the purposes of this reporting?

We use the term “autistic community” to refer to autistic people of all ages. The term “autism community” includes autistic people but also refers to a wider range of people who are not autistic but are stakeholders in autism research. The autism community therefore includes parents of autistic children, practitioners and policy makers.

Community involvement can mean inclusion in research of any members of the autism community – including but not limited to autistic people.

In some cases, such as transdiagnostic or cross-cultural research, other community stakeholders who don’t have a personal connection to autism may also be important partners for your work. Community involvement at its broadest therefore includes any collaboration or partnership with individuals or organisations from outside the academic or research establishment.

5. What is the definition of “community involvement”?

Community involvement is a broad, umbrella term covering any kind of co-working with representatives from a community beyond the academic establishment.

Community involvement could include formalised co-production, community-based participatory research (also known as CBPR) or citizen science. Community members could be involved in priority-setting exercises, co-design of new resources and measures, or contribute to study oversight as part of a stakeholder reference group. Community involvement might also take the form of more informal engagement via social media or personal networks.

If you have had input to your research from one or more people, or organisations, from outside academia then you can report this as community involvement.

6. How much detail is needed in the “community involvement” statement?

One of our goals in requiring a community involvement statement is to facilitate sharing of methods. For this reason, please try to report the types of people / organisations who took part and their roles in such a way that readers can learn from and build on your approach. However, we do not expect the same level of detail as we do from your experimental or observational study methods since future researchers will not need to precisely replicate your methods.

7. What are my options if I, or a co-author, is a member of the autism community?

There are different options available, depending on the precise way that this applies to you and your co-authors.

First, some of your co-authors may be community partners, who have become co-authors because of their involvement in the research but are not academics or researchers themselves. [This paper provides an example of this kind of co-authorship](#). In that case, you will want to report the ways in which your community co-authors played a role in the research in your community involvement statement. It is not necessary to specify named people as having a specific diagnosis or other connection to autism. You can write that the research was “*led by a diverse group including a number of autistic people*” or that “*the researchers recruited an advisory board which comprised autistic people, parents of autistic children, and two clinical practitioners*” for example.

Second, you or a co-author may be an academic researcher who is also a member of the autism community. Again, it is not necessary to specify named people as having a specific diagnosis or other connection to autism. Options to declare this kind of community representation within the research team include: “*The research was led / co-led by an autistic researcher*” or “*the research was led by a neurodiverse team*” or “*there was autistic representation within the research team*”. You can create equivalent statements if members of the research team are also parents of autistic children, or are otherwise part of the autism community.

Following these statements, you could also add “*There was no other community involvement in this work*” if that applies. Or you could describe any other ways in which autism

community perspectives were incorporated into the work – including any ways that your research team operated an inclusive research model during the reported project.

Third, if you are a researcher and a member of the autism community, but your study didn't include any involvement with community members from beyond academia, you have the option to simply state that there was no community involvement in the study.

8. What should I write if there was no community involvement in my study?

We recommend including a statement that states “*There was no community involvement in the reported study*”.

9. If I have no community involvement in my study will it affect my work's chance of being published in *Autism*?

No. We will not prioritise community involvement nor penalise studies that do not report community involvement.

However, there may be cases where a lack of community involvement is viewed as a flaw in a study. For example, in work examining community experiences of / attitudes to sensitive topics (e.g. gender non-conformity, genetic screening for autism) the editors or reviewers at *Autism* might judge that a lack of community involvement prevents the paper from drawing accurate conclusions from the data. Likewise, the creation of new therapeutic or educational supports would normally benefit from some element of co-design.