We promise to involve you.
Autistica is the UK’s autism research charity. We exist to give every autistic person and their family the chance of a long, healthy, happy life through research. To achieve our vision we need you, the people we serve. Doing this will ensure that research has the best possible impact on your life. That’s why we have this plan for involving people in research.

In September 2017, we launched a new research strategy underpinned by the UK’s first national autism research network: Discover. Run by Autistica, Discover will connect autistic people and their families with autism researchers, local charities, support groups and NHS Trusts.

Through Discover, we will increase involvement of autistic people and their allies at all levels of the research process. This means research will address the needs of autistic people and bring us closer to a better future for autistic people.

What do we mean by public involvement?

According to the National Institute of Health Research, public involvement is “research being carried out with or by members of the public rather than to, about or for them”. There are different levels of public involvement, from participation in research studies at the most basic level, to community-led research at the highest level.

Our definition of autistic people and their allies includes:

- **autistic people**
- **parents or relatives of autistic people**
- **carers of autistic people**

Involving autistic people and their allies is one of Autistica’s central priorities, and is reflected in our guiding principles:

- We support the autism community to have your say – you lead what we do.
- We create ways for the whole community to meaningfully contribute to our work.
- We are inclusive – we want to represent everyone, including those whose voices are rarely heard.

“Autism research – informed by actual autistic people – is the only way to achieve progress in improving the lives of autistic people”

Jon Adams, autistic advocate
Why should you get involved?

You can tell us what matters

We know that a lot of autism research doesn’t match the priorities of autistic people and their families (Pellicano, Dinsmore & Charman, 2013). We want to change that by having you involved at every stage of our research.

Autistic people and their families can

- make sure the research that gets funded is what matters most to you
- ensure that autism research is conducted in a way that is autism-friendly and adapted to your needs
- receive the latest, most accurate information on autism research discoveries.

“Friday was just fabulous for Thomas because another attendee shared the troubles he had at school etc., and Thomas could see that he was doing well. Thomas has found the whole experience really inspiring. Loved being involved”

Helen, autistic advocate and parent, referring to Autistica’s mental health campaign workshop
How can you improve research?

Help us design suitable studies

Involving autistic people in the process of designing studies will lead to improvements in the way research is conducted, for example:

• **Choosing research questions**: By consulting with autistic people and their allies when choosing questions to research, researchers will know they are focusing on the areas that are the greatest priority to autistic people.

• **Study design**: Working with the autism community can help researchers to make study materials, such as questionnaires, that are appropriate and autism-friendly.

• **Improving the experience**: Gaining insight can help researchers ensure that taking part in research is a positive experience. For example, you may suggest that researchers should feed back to participants about the results of the study they’ve taken part in.

With your help researchers can:

• ensure their research is important to autistic people

• improve their study design

• share their work more effectively

• make sure their research is useful in the real world

• make the research experience a positive one.

“Positive partnerships with community members and organisations can help with recruitment to studies, and increase the likelihood of that holy grail – translation of findings into practice”

Sue Fletcher-Watson, Researcher, The Psychologist magazine
Great day talking mental health with @AutisticaUK! #JoinDiscover to help give the #ActuallyAutistic view on research” @mindtheflap

Georgia Harper, autistic advocate, referring to Autistica’s mental health and autism research priorities workshop
How can you be involved?

Level 1: Become a Discover member
Learn about research and opportunities to take part

When you join Discover, you’ll receive newsletters with information about trials and our latest research news. We will also tell you about opportunities to sign up to our research databases and participate in research studies.

Level 2: Autism Insight Group (AIG)
Help us shape research

The Autism Insight Group will shape the research process. We will contact you whenever opportunities arise, but there is no minimum commitment. We offer science training to all Insight Group members. We’ll ask you to tell us what activities you may be interested in when you join. These may include the following:

- Working with researchers to develop and design proposals
- Monitoring research projects as they progress
- Advising on the development of autism-friendly materials, such as questionnaires
- Providing early input into proposals
- Giving feedback on research design
- Attending researcher engagement events
- Acting as a media spokesperson on a particular study. You would receive training for this.
Level 3: Autism Study Groups (ASGs)

Be part of creating innovative research ideas, driven by the community

The Autism Study Groups will focus people with experience of autism, researchers and other professionals, on the key areas of priority that have been decided by autistic people and their families. Grants will be available.

Study Group members commit to focus on a particular research area for three years. Study Groups will meet twice a year, and stay in contact between meetings. If you are a member of the Autism Insight Group, you might want to join an Autism Study Group as well. These will be the most effective way of speeding up research in a specific area.

There will be four Autism Study Groups in the first year. These will be:

Physical health • Language and communication
Mental health • Complex needs

Payment

We believe that appropriate financial support is important to help more people get involved in research. Autistic people, relatives and carers taking part in involvement activities will be offered a fee in line with the National Institute for Health Research’s INVOLVE guidelines.
How have we involved autistic people in research already?

• Deciding research priorities
  In 2016, we gathered views from 1,200 people with experience of autism, asking their top three questions for autism research. The top questions identified guide our funding strategy.

• Workshops
  We hold workshops where research ideas are generated by autistic people working together with researchers and other professionals.

• Strategic direction
  Our panels include autistic people and family members. This ensures their views influence the strategic direction of Autistica.

• Commissioning
  Research proposals are reviewed by autistic people and parents on Autistica’s Science Advisory Group. This directly influences funding decisions.

• Participation
  Autistica funds the ASD-UK (Autism Spectrum Database UK) and AASC-UK (Adult Autism Spectrum Cohort UK) programmes, which give autistic children and adults the opportunity to take part in high quality research.

  “The day involved an interesting set of tasks and well organised group activities, allowing each of us to express our opinions and share our experiences effectively. After discussing research priorities within the smaller groups, we joined together to narrow down and decide upon the final research priorities. This part of the day sparked open and detailed discussions, and I got a real sense that we were already making a difference to autism research”
  Mair Elliott, autistic advocate, referring to the James Lind Alliance workshop

  Example: Your research priorities
  We believe that research should answer questions raised by people with experience of autism. To understand what these questions are, we led a James Lind Alliance Priority Setting Partnership in 2016 with a number of partners, including the National Autistic Society, Autism Research Trust and the Autism Alliance UK.

  How autistic people were involved
  We asked 1,200 people for their top three questions for autism research.
  • The 3,331 questions we received were then sorted into groups.
  • A final top ten list was then created in a workshop attended by autistic people, parents, and professionals.

  What did this do?
  Our research strategy now addresses many of these priorities, and we are working with partners to answer all of the top ten questions.
Active consideration of autistic people’s comfort and respectful discourse; wish I could bottle and take these attitudes everywhere”
@Kabieuk

Kable Brooke, autistic advocate, referring to Autistica’s ageing and autism summit.
Other ways Autistica is increasing involvement

• Small grants for autistic researchers will enable more autistic people to take their first step into research.
• Our contracts for research grants insist that researchers funded by Autistica engage in meaningful involvement.
• We are consulting with early career researchers to understand how we can better support them to meaningfully engage with the autism community.

Autistica’s commitment
We aim to:

20,000 autistic people and family members engaged in research by 2021
recruit 50 people to the Autism Insight Group over the next two years
set up and manage four Autism Study Groups over the next two years.

In line with these plans, we will measure the impact of our involvement activities and publish a yearly summary of our activities.

This involvement promise
• autistic people
• research charities
• autism researchers

“...It feels good to be involved in your work to improve people’s lives, but it’s also a great learning experience for me – finding out what you do and hearing different perspectives. Huge thanks for the opportunity you’ve given me”

Celia, autistic advocate, referring to Autistica’s mental health campaign workshop

Under-represented groups
Some people may be under-represented in autism research, including:
• people with learning disabilities
• people with minimal verbal ability
• autistic adults, especially older adults
• people from lower socio-economic backgrounds
• black and ethnic minority groups
• women and girls.

By increasing involvement in research at all levels, we plan to increase involvement with these kinds of people too. When we need to, we will consider specific measures to support groups who are often excluded.
Resources

To find out more about involvement and good practice, you may find the following resources useful.

- Your questions: shaping future autism research https://www.autistica.org.uk/our-research/our-research/your-research-priorities
- INVOLVE http://www.invo.org.uk/ policy on payments and expenses for members of the public, including INVOLVE group members http://www.clahrc-ndl.nihr.ac.uk/documents/mpi/05-involvepaymentpolicy.pdf
- The Participatory Autism Research Collective https://participatoryautismresearch.wordpress.com/

Articles


autistica.org.uk/take-part