

NEWS

# Six steps to engaging in participatory autism research

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The August launch of the U.K.-based autism research project Spectrum 10K sparked a firestorm of negative comments about the study's aims from autistic people and their allies. The researchers have **paused the project** while they seek more guidance from autistic community members.

"They're backtracking and backpedaling furiously, and it was completely avoidable," says **Sarah Douglas**, who is autistic and has advised several autism researchers across the United Kingdom. Projects like Spectrum 10K should involve autistic people from the start, she says.

This idea, known as 'participatory research,' calls for including autistic people in all aspects of research, from setting research agendas and writing grants to designing studies and interpreting findings. A growing number of autism researchers are **adopting this approach**. And some academic journals are emphasizing it, too. As of this year, the journal *Autism* requires manuscripts to **include a statement** on how the researchers have partnered with autistic community members. And *Autism in Adulthood* includes **autistic editorial board members** and peer-reviewers.

But the bulk of autism research still involves autistic people only as study participants, not collaborators, experts say. One reason: Many researchers may be unsure what **counts as participatory research** or where to start, a June study suggests. Adding to the confusion is the fact that some work that **claims to be participatory** turns out not to be, according to 2020 findings. "The idea of participatory research has sort of exploded without necessarily the structures to support it very well," says **Christina Nicolaidis**, professor of social work at Portland State University in Oregon.

When done well, however, participatory research has a host of benefits. Importantly, the autistic community gains a voice in studies that involve it. “I know it must sound daunting to researchers,” who might be concerned about extra work and other obstacles, Douglas says. “But actually, this really matters,” she says. “It’s changing the culture.”

On top of that, scientists are likely to collect better data or **design better programs** in light of community input, experts say. *Spectrum* asked autism researchers (**some of whom are autistic**) and their autistic partners for advice on how to involve autistic community members in scientific studies. Here are their top tips.

## 1. Look inward.

Before embarking on participatory work, it’s important to adopt the right mindset. First, reflect on how your work aligns or may be out of step with the priorities of the autistic community. Ask yourself, “Why am I doing this work?” and “Is this research helping autistic people?” Doing so will set the stage for establishing meaningful collaborations with autistic partners.

Next, consider your own biases. “You have to really recognize that the reality is we live in an ableist world — we live in a world where autistic people are marginalized,” says Nicolaidis, who co-founded a **participatory program** called the Academic Autism Spectrum Partnership in Research and Education (**AASPIRE**). “You’ve got to kind of think through, ‘How does that actually affect what I do?’”

Understanding those biases will help you keep an open mind. “Go in genuinely prepared to change what you might do in response to what you might hear,” says **Sue Fletcher-Watson**, professor of developmental psychology at the University of Edinburgh in the U.K.

Third, take the time to learn more about autistic culture and the **sometimes rocky relationship** the community has with autism research, Nicolaidis says. Read the work of autistic people, from blog posts to the growing number of journal articles authored by autistic researchers. (This September article by an **autistic autism researcher** would be a great place to start.)

Know that most autistic partners are likely to prefer identity-first language — referring to those on the spectrum as ‘autistic’ instead of as ‘people with autism,’ says Douglas, who has collaborated with Fletcher-Watson. It’s also important to rethink autism’s so-called ‘deficits’ and **embrace the many strengths** autistic people possess. “It’s not just using the language that’s acceptable to the autistic community,” she says, “It’s actually genuinely engaging in the theories and attitudes that this language represents.”

## 2. Meet autistic people.

You then need to meet autistic people and start forging relationships. If autistic people take part in

your research already, you may be able to draw from that pool. But to build from there or if you're just starting out, try social media. Many autistic people are active on Twitter, for example. But tread carefully. "Social media is a rather fiery place," says autistic autism researcher **Damian Milton**, senior lecturer in intellectual and developmental disabilities at the Tizard Centre at the University of Kent in the U.K. Just listen at first, paying attention to what matters to autistic people, he suggests.

When you start to engage online, be sure not to barge into spaces that are meant exclusively for autistic people, Fletcher-Watson says. If you aren't autistic, avoid using hashtag **#ActuallyAutistic**; try using **#AskingAutistics** instead. And be sensitive. Some autistic people may have had negative experiences with research or find it difficult to trust people, Douglas says. "We can be quite fragile," she says. "We need people that are genuine and kind and are absolutely clear with their aims and intentions."

Getting out into your community is another option. Host local events or attend those run by autistic people to see what's happening on the ground, says **Laura Crane**, associate professor at the Centre for Research in Autism and Education at University College London in the U.K. "Don't expect people to just kind of land on your doorstep," she says. But please check with the organizers of any community event to make sure you are welcome, she adds.

Looking locally can also help you identify needs specific to the autistic people in your area. For example, after meeting an autistic author and blogger named **Caroline Hearst** at an event, Crane helped her evaluate a program she was running to **support newly diagnosed** autistic adults. In this setup, Hearst generated the research idea, and Crane led the scientific work to explore it. "That's how I would see [participatory research] ideally happening," says Hearst, who founded the U.K.-based autistic support community **AutAngel**. Working with Hearst taught Crane a lot about making her research more accessible, Crane says, and the pair continue to collaborate.

### 3. Assemble your team.

Next, it's time to invite autistic people to be partners in your work. It's best to do this early in the research process, even before you have funding, says autistic activist and blogger **Jack Welch**, who has collaborated with Crane. Welch is also an advisor for several organizations, including **Mencap** and the **National Health Service England**. In this way, Welch says, we are "helping them to make the right decisions at the time that they can be influenced, as opposed to just providing rubber stamps of approval when it's too late."

If you are new at this, start by collaborating with just one or two autistic people whom you trust and get along with. "Some of this is like dating," says Nicolaidis, whose participatory work stemmed from an **initial partnership** with autistic systems scientist **Dora Raymaker**. "You're not going to always mesh with everybody."

Building these relationships is similar to establishing traditional academic collaborations: The

emphasis should be on an ability to exchange ideas and shared research priorities. Think carefully about whom you ask, says autistic researcher **Jackie Ryan**, a doctoral candidate in Sandy Thompson-Hodgetts's lab at the University of Alberta in Edmonton, Canada. You don't just want 'yes' people, she says. "You want people who are going to authentically critique what you do, so that you can grow and learn from their experience and do better research." Fletcher-Watson further warns researchers not to rely solely on the input of autistic academics, whose perspective also comes from their scientific training.

But do look for people with relevant experience, Nicolaidis says. For example, if you are studying autistic people with intellectual disability or who are struggling with an **eating disorder**, reach out to autistic people with those lived experiences. Resources, such as the **Insight Group**, formed by Autistica, a U.K.-based funding organization, can help connect researchers with autistic community members interested in shaping autism research.

#### 4. Share the power.

Each level of participatory work comes with its own power dynamics. For example, autistic people might serve as consultants on a study but have no actual influence over it. "That's better than nothing," says autistic researcher **Jac den Houting**, a postdoctoral research fellow in **Liz Pellicano**'s lab at Macquarie University in Sydney, Australia. But if that's the only approach that works under your circumstances, be sure to communicate this setup at the outset, den Houting says.

Research becomes truly participatory when scientists share decision-making power equally with their autistic collaborators. To accomplish this, be careful that the voices of autistic partners aren't lost among the academics or even caregivers of autistic people, says autistic advocate **Julianne Higgins**, who has worked with den Houting as a peer researcher. "Things to look out for [are], at each stage, whose voice is listened to," Higgins says.

Consider a decision-making method that gives each team member veto power. Instead of using majority rule, Nicolaidis and her team **vote using their fingers** — one finger, meaning full approval, up to five, reflecting total rejection. If anyone vetoes a decision, the discussion starts anew until the group can reach consensus.

Autistic voices should also have equal say in administrative decisions that influence research. For example, autistic adults sit on a review committee that determines whether researchers can recruit families participating in **SPARK**, the largest genetic study of autism. (SPARK is funded by the Simons Foundation, *Spectrum*'s parent organization.) Similarly, Douglas served on an interview panel for hiring a researcher to help run an autism study at the University of Bristol in the U.K. "Things like that are huge," she says. "They're not just gestures. It's not box-ticking."

Scientists can even co-produce their participatory approach with autistic partners. "I've always

found that the most enjoyable and most collaborative way of doing participatory research,” says **Sarah Cassidy**, assistant professor of psychology at the University of Nottingham in the U.K. Consult your autistic collaborators on decisions about whether to host team meetings in person, online or in a hybrid format, and on what other accommodations might be necessary, such as making materials available in advance or providing captioning.

It’s also important to reflect this power-sharing in publications. “Whenever I see a study that describes itself as participatory, and then you look at the author list and there’s no autistic author, then it’s kind of a red flag,” says **Kristen Gillespie-Lynch**, associate professor of psychology at the College of Staten Island and the Graduate Center of the City University of New York. It indicates autistic people weren’t necessarily involved on a meaningful level, she says. Including autistic partners as authors on papers may involve creating a lay-language version of a manuscript draft, for example, or reading the draft out loud to make sure every author can provide feedback.

## 5. Pay people.

As members of your research team, your autistic partners should be paid — ideally, at a rate appropriate for academic collaborators, not minimum wage, Fletcher-Watson says. “It shows that their time is valued and that their expertise is recognized as expertise,” she says.

To make sure funds to do this are available, you may need to build participatory work into the budgets of your grant proposals, Ryan says. “Be thinking about it from the very beginning.” You should also be sure your partners know what their compensation, if any, will be from the start. This is another area where transparency is key, she says.

Paying your partners may also involve some red tape, given that they are typically not employed by your institution. For example, your partners may have to submit invoices and complete tax forms, so be sure to offer to assist them with those documents.

## 6. Be nimble.

Whatever your plan, it may need to change. For example, making sure everyone can contribute regardless of background may involve being flexible about how team meetings are conducted. This type of work often takes more time, Nicolaidis says, especially when big issues arise and the team has to reach consensus on how to solve them. And what works at first may not later on, as new team members join and the goals of the group change. Nicolaidis and her team use a quick ‘keep/change’ exercise at every meeting, in which partners can say what’s working and what needs to be phased out. “That constant kind of improvement, figuring out how to tweak things, how to do them better, really, really matters,” she says.

Remember it’s OK to get things wrong sometimes, Fletcher-Watson says. Just like science itself, participatory work is a process — you’re always learning from your mistakes. “It’s normal to feel

that you wish you had done more, and that doesn't mean you should give up," she says.

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