



This is what Spectrum 10K has said about:

Autistic involvement in the design of the study

1. How were autistic people involved in the design and setup of Spectrum 10K?

No autistic people were involved in the design of Spectrum 10K prior to the Wellcome Trust providing funding for the project. After Spectrum 10K was funded, we recruited an Advisory Panel made up of the following people:

- 3 autistic adults.
- 3 non-autistic parents/carers of autistic children.
- 2 clinicians (clinical psychologists/psychiatrists).
- 1 representative from the autism-related charity Autistica.

We asked our Advisory Panel to do the following:

- Tell us what they thought were the most important areas of research for autistic people. Together, we agreed that these areas included mental and physical health conditions, education, social relationships, diet, sleep, employment, and income.
- Review the list of questionnaires that participants in Spectrum 10K would be asked to complete and suggest changes. Based on their feedback, we added whole new questionnaires about vulnerability and quality of life. Together, we also agreed that it would be important to ask questions about autistic and sensory traits, anxiety, depression, obsessive compulsive disorder, developmental milestones, and camouflaging (or masking).
- Review public-facing information, including the information sheets, that we would provide participants in Spectrum 10K. Based on their feedback, we made some changes to the information to make sure that they were clear.

We incorporated the feedback of our Advisory Panel into the creation of the Spectrum 10K study protocol, which is the manual that the research team will follow as they carry out the study.

2. Why were relatives and other stakeholders involved?

We invited parents, psychologists working with autistic people, and an autism charity representative to take part in the Advisory Panel to represent the voices of autistic children as well as to gain insight from those who work closely with autistic people and have an interest in their wellbeing.



3. What are you going to do to engage autistic people more widely?

We have heard the feedback from the wider autism community online and we recognise that we need to consult with more and diverse autistic people and carers.

In response to the feedback since our launch we commissioned Hopkins Van Mil to work with us on a Spectrum 10K consultation. As a result we have worked with autistic people and carers to co-design a consultation strategy and begin a wider consultation process.

The Spectrum 10K consultation is being co-led by Hopkins Van Mil, which is an independent agency, by Leneh Buckle, who is an autistic researcher working on a freelance basis for Hopkins Van Mil, and the Spectrum 10K team.

Some of what we will be asking for feedback on includes:

- How to make information about the study as clear as possible
- How to make the study safer, more ethical, or improved in all aspects of its work
- What specific issues do autistic people want us to research
- How should our data access request process work so autistic people and families feel comfortable sharing
- Who should be on the Data Access Committee
- What criteria should the Data Access Committee use to decide whether to share data
- How we should manage data sharing after the project has ended

This feedback can be provided during the consultation in:

- A consultation survey
- A series of online webinars and discussion groups
- One to one interviews

Consultation activities will be open to autistic people, their families, researchers, and health and social care professionals.

These activities will provide opportunities to hear from the diverse voices of the autism community so that we can collaborate and shape Spectrum 10K together.

We want to ensure that the autism community is meaningfully involved in this project.

The Spectrum 10K team will continue to consult the autism community, being transparent with our process and our goals, to ensure we can work together throughout the length of the project.



4. What issues will be covered when you engage autistic people more widely?

In response to the feedback since our launch, we have co-designed a consultation strategy with autistic people.

Some of what we will be consulting about might include:

- How to make information about the study as clear as possible
- How to make the study safer, more ethical, or improved in all aspects of its work
- How should our data access request process work so autistic people and families feel comfortable sharing their data (genetic, questionnaire, and linked to electronic health records)?
- Who should be on the Data Access Committee?
- What criteria should the Data Access Committee use to decide whether to share data with external researchers?
- How should we manage data sharing after Spectrum 10K has ended?

5. What is the ongoing role of Ambassadors in Spectrum 10K?

Ambassadors were non-paid members of the autism community who were interested in the study and in promoting it. As of 23rd May 2022 we have decided to end the role of Ambassadors for the study. We are very grateful to our Ambassadors for the support they have provided, but it will be impossible to keep Ambassadors up to date as the consultation progresses because things can change very quickly. This risks placing Ambassadors in a situation where they are asked questions that they cannot answer, simply because we have not had time to bring them up to date. We want to avoid any risk of public confusion about the project and focus entirely on the consultation.