



This is what Spectrum 10K has said about:

Data Access Committee and safeguarding against future eugenics

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1. How exactly will decisions about who can access Spectrum 10K data be made?

We will co-designing our data sharing policy with the autism community. This will include setting up a Data Access Committee made up of researchers, autistic people, and parents and caregivers of autistic people. The Committee's exact membership, structure, methodology, and decision-making processes will be decided during our consultation with the autism community. We will publish all these details before we ask participants to sign up to Spectrum 10K.

No data will be shared without the approval of the Data Access Committee. To apply for access to Spectrum 10K data, external researchers will have to submit a full proposal to the Committee that describes what their research is, who is involved in the research, what they will use Spectrum 10K data for, and what the value of their research will be for science and the autism community. The Data Access Committee will evaluate the application using a checklist that is being co-designed with the autism community. The checklist will be designed to ensure that the proposed research is consistent with the aims and values of Spectrum 10K and has been approved by an independent research ethics body. We will publish the checklist on the Spectrum 10K website along with the rest of our data-sharing policy and summaries of any approved research projects, so that participants and other members of the public can know about all the research that is being carried out with Spectrum 10K data.



The Data Access Committee (also sometimes referred to as the Data Committee Steering Group) will not approve any access to Spectrum 10K data by researchers who are seeking to develop a prenatal test for, or to cure or prevent, autism.

To be approved for access to Spectrum 10K data, external researchers will have to sign a formal and legally binding data transfer agreement with the University of Cambridge that states explicitly what they can and cannot use the data for. They will also have to agree to submit any scientific papers that they write using Spectrum 10K data to the Data Access Committee for scrutiny before they can submit the paper to an academic journal for publication. This will enable the Data Access Committee to make sure that the research carried out with Spectrum 10K data is consistent with the terms on which access to Spectrum 10K data was originally granted.

2. Will autistic people have a say on who gets access to the data?

Yes. The Data Access Committee will include autistic people. The exact make-up of the Data Access Committee and the data sharing policy that the Committee will follow when it decides who can access the Spectrum 10K data will both be co-designed with members of the autism community during our consultation.

3. Will Spectrum 10K sell data?

No. We will not sell data at any point, during or after the study. We have no commercial motive for conducting this research.

We may share anonymised data with commercial collaborators who are conducting ethically approved research in line with the aims and values of Spectrum 10K. We do not want to exclude the possibility that future research may benefit autistic people just because it is being conducted by non-academic companies. Commercial collaborators will go through exactly the same process for requesting access to Spectrum 10K data as will academic collaborators. This process will make sure that any commercial collaboration is in line with the ethical values of Spectrum 10K. Examples of possible commercial collaborations include the development of a drug to alleviate a specific type of epilepsy or gut difficulty relevant to some autistic people. Such research is typically conducted in commercial collaborations.

We recognise that some participants may not wish their data to be shared with commercial collaborators, so this will be optional. At the point of signing up to participate in Spectrum 10K, participants will be asked to tick a separate box to indicate that they consent to their data being shared with commercial collaborators. Participants who do not consent to their data being shared with commercial collaborators will still be able to take part fully in Spectrum 10K.



4. What data will be shared and why?

Only approved members of the Spectrum 10K team will be able to access the Spectrum 10K data. They will only be able to access the data that they need and limited pre-approved access to data will be provided. Only specific researchers in the team will have approval to access personally identifiable data which will be limited to the Database Manager and approved individuals for data management purposes.

In the future, we would like to share Spectrum 10K data with other researchers. This is important for lots of reasons. First, it makes science more transparent by enabling results to be replicated. Second, it prevents other researchers from wasting resources by collecting the same data in future. Third, it maximises the possible public benefits from the data by enabling different researchers with different areas of expertise analysing the same data in different ways. For example, as a parallel, the UK Biobank contains questionnaire, genetic, and medical data from 500,000 adults. Researchers who have been given access to this data have been able to identify people who need regular screening for breast cancer and heart disease.

We will only share anonymised Spectrum 10K data with external researchers who are conducting ethically approved research in line with the aims and values of Spectrum 10K. Only researchers who have been approved by the Data Access Committee will be able to access Spectrum 10K data. They will only have access to the data that they need for their research, never to participants' personally identifiable information, and will only be able to use the data for the purposes of their research.

We will not share any data with the police unless we are legally obligated to do so. We will never share data with employers, local authorities, or anybody else who will not use the data purely for research purposes approved by the Data Access Committee.

5. Can you guarantee that our data will be safe and never get into the hands of those who would wish to harm us?

Your data will be kept strictly confidential. Any data you share with us will be stored under a unique ID in a process known as pseudonymisation. This means that you cannot be identified from any of the samples or data you provide.

Spectrum 10K data are being securely stored on a University of Cambridge safe-haven (ISO27001 accredited). Your data will be stored on secure servers located at the University of Cambridge and will only be accessible by approved Spectrum 10K researchers.



We will co-design a sharing policy with the autism community so that, eventually, data from Spectrum 10K participants can be shared with collaborators in the spirit of advancing research. It will not be shared with anyone to develop prenatal testing for autism or a cure for autism.

Your anonymous medical and health data will be stored separately from your personal details.

All data collected will be collected in line with the Data Protection Act 2018 and GDPR (General Data Protection Regulations).

Data collection will also comply with the Common Law Duty of confidentiality. You can read more about it at:

<https://researchgovernance.medschl.cam.ac.uk/information-governance-storage-of-research-participant-data/secure-data-hosting-policy/>

We have mechanisms in place to keep your data safe. One of these is that we will set up a Data Access Committee, made up of autistic people, their family members, and scientists, to ensure that any scientist who applies for access to our data has values that align with ours, including opposing the development of a prenatal test for autism, opposing the prevention of autism, and opposing the development of a cure for autism.