

## **Spectrum 10K FAQs**

### **Genetics**

**Q: How do you believe that genetic data will be used to help Autistic people? How does understanding genetic factors help you to support autistic people and their families?**

Genetic data can be helpful in a few ways, especially for co-occurring conditions. First, genetic data can help identify meaningful subgroups of autistic individuals. This can allow for different types of support. This includes rare syndromic forms of autism with specific co-occurring conditions. One example is the gene CHD8 where autistic individuals are more likely to have severe gut difficulties. Some co-occurring conditions like epilepsy and certain forms of gut difficulties are overwhelmingly genetic. Understanding the genes underlying these conditions can help develop better medical support targeting these conditions in autistic people. Other co-occurring conditions like sleep issues, epilepsy, hypermobility, and EDS and depression are partly genetic, and arise from the interaction between our genes and our environment. Here, capturing genetic information in concert with sleep difficulties and depression and environmental factors can identify subgroups of autistic people who may have very different reasons for sleep difficulties and depression. For some of these individuals we may be able to provide better medical support for these conditions. A third factor is understanding who will respond to what support. For instance, people may respond differently to different support for things like depression and anxiety. Unfortunately, there is little information to know how people will respond and what works for each individual. This means that people may spend years trying different options. Using genetics and environmental factors may help us build better models to better predict who responds to what. We have provided a video which explains some of these here: [Spectrum10K Genetics Explainer - YouTube](#)

**Q: Why do you need genetic information? Why isn't the survey enough?**

Autism is overwhelmingly genetic. As much as 80% of variation in autism is thought to be genetic. However, importantly, many co-occurring conditions (e.g. dyspraxia, motor difficulties, ADHD, depression, sleep difficulties, anxiety) are genetic to various extents. We understand that disability ultimately results from a person's biology in the context of society. To this end, whilst survey results provide very helpful results they provide incomplete results in understanding some of these critical co-occurring conditions.

### **Data safety and data sharing**

**Q: Will sharing the data with others mean that it can be used by future studies which can be eugenics-based even if this isn't?**

No data will be shared without stringent oversight and governance. An internal study Steering Committee comprised of the senior scientific investigator team and suitably qualified experts, including autistic individuals, will review and oversee any requests to access data. To access any

anonymised data collected by us researchers will have to submit a full proposal, which then will have to be approved by the dedicated panel. To be approved it must align with our aims of no cure, no eugenics, not harmful etc. and have value to science and the autism community.

**Q: How are you ensuring that the anonymised data cannot escape your control of it?**

All approved research will need to sign a legally binding contract, which will clearly spell out the scope of the research that can be conducted.

**Q: Can the data be safe and secure?**

The data is being securely stored on a University of Cambridge safe haven, ISO27001 accredited. You can read more about it at <https://researchgovernance.medschl.cam.ac.uk/information-governance-storage-of-research-participant-data/secure-data-hosting-policy/>

**Q: Even though it's optional, why do you say that you are open to commercial collaboration?**

Science discovery and research is a fast moving area. Some companies either today or in the future may be involved in specific research that's not being conducted in academia. One such example may be the use of machine learning to identify who responds to what therapies for depression and anxiety, thereby tailoring support for people with depression and anxiety. We do not want to exclude such research from being carried out just because it's being carried out by non-academic companies. All research proposals will go through the same process and be vetted by the internal team as mentioned above.

**Q: Will the data be shared with the police/future employers/anyone else that can victimise me/my child?**

We will not be sharing any data with the police, employers or anyone else. The data we collect will be for research purposes only for use within the scientific community.

**Q: Will my data be sold on at any point during or after the study?**

No, your data will not be sold at any point during or after the study.

## **Harm and eugenics**

**Q: Are there autistic people involved in the process? How will you identify what is and is not eugenics. These teams have been known to lie in the past.**

Autistic people will be part of our committee who makes the decisions about who to share data with, we are in the process of setting up this committee. Any data shared will be subject to a contract between research institutes which will explicitly state what it can and can't be used for. The wellbeing and support of autistic individuals and the autism community is our highest priority.

**Q: How are you defining wellbeing and what's of value to the autism community?**

We are defining not harmful as research that can potentially improve the quality of life and wellbeing of autistic individuals. As mentioned earlier, all research proposals will be vetted by a team

of individuals which will include autistic individuals. Only once it meets our oversight and governance standards and ethical principles will data be shared.

Spectrum 10K uses the term 'wellbeing' to include physical and mental-health conditions, such as gastrointestinal problems, epilepsy, anxiety and depression, as well as lifestyle factors that influence the health and daily quality of life for autistic individuals. Spectrum 10K has consulted with an advisory panel, consisting of autistic adults and parents of autistic children, about their views on wellbeing and quality of life. The information collected in this study covers various aspects of mental and physical health but it is, by no means, an exhaustive definition of wellbeing.

**Q: Do you support a cure or eugenics?**

We have clearly stated on our website that we are not searching for a cure and are opposed to eugenics.

**Autistic people's involvement**

**Q: Outside of the pool of people being researched, how many autistic people are on your staff?**

Unless a staff member has publically disclosed this we're not able to provide that information.

However, during the process of setting up this study, we have worked with an advisory panel consisting of autistic adults and parents/carers of autistic children and autistic adults with ID who have helped us with this project. Four are autistic individuals, five are parents of autistic individuals, and two are clinicians.

**Autism Speaks**

**Q: Is any of the funding for this project from Autism Speaks? Whether directly, or indirectly. Is Autism Speaks, perchance, directing or otherwise influencing this project?**

Autism Speaks is not involved with our project, we have not spoken to them about it. The Wellcome Trust funds many projects but we are not working with Autism Speaks and have no plans to do so. We are not part of the Autism Genome Project. The Autism Genomics Consortium is a consortium that we are planning to set up on the back of this project that investigates how we can use environmental and genetic data to better understand co-occurring health conditions in autism.

**Ethics and consent**

**Q: How can you ask for my child/carer's DNA or information as it's not mine?**

Whilst children under the age of 16 years cannot legally provide consent, children who can read can provide assent. An explanation of the study is provided and children are enrolled in the study only if

they agree. For all children six and above, we have created easy to read age appropriate information sheets (these can be found at <https://spectrum10k.org/information-sheets/>). An assent form is provided for children in addition to a parent consent form. This is typical of studies (genetic and otherwise) that involve children.

**Q: How has participation of autistic individuals with limited communication to participate been designed? How has this been vetted?**

It is important to us that Spectrum 10K is inclusive of the full autism spectrum. To facilitate and support involvement of autistic individuals with intellectual disability or those who are without capacity we have consulted with experts in Intellectual Disability as part of the design and consent process. We have included easier read Participant Information Sheets for adults with Intellectual Disability. The British Medical Association Capacity Assessment tool has also been built into the website to facilitate capacity assessment for adults without capacity who are being supported by a carer or family member. The study has been reviewed and ethically approved by specialist ethics committees who oversee the safety of children and adults without capacity within research studies.

**Q: Has this study been peer reviewed?**

This study has been peer reviewed as part of the funding application and as part of the ethics application procedure. An independent external review and report has also been required for our two specialist NHS ethics committees.