



This is what Spectrum 10K has said about:

Data security and privacy

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1. How exactly will Spectrum 10K data be stored and how secure will this be?

Spectrum 10K data will be stored in a Spectrum 10K database on the University of Cambridge's Secure Data Hosting Service, which is a "Data Safe Haven" with ISO 27001 certification. This means that the data will be fully secure. It is password protected, only accessible by approved members of the Spectrum 10K team, only accessible from virtual desktops without access to the internet, and unable to be copied to any other device or server. This data is pseudonymised, so that researchers will not be able to identify participants while they carry out research.

Genotype data will be stored on the Secure Research Computing Platform (SRCP), which is a secure private tenanted cloud platform for the storage and processing of level 3 confidential data and sits within the University of Cambridge. The platform requires 2-factor authentication, is ISO 27001 certified and is backed up.

Saliva samples are stored and analysed at a licensed laboratory and biorepository. Samples are only labelled with a barcode and the laboratory and biorepository do not have access to any personally identifiable information. This is also the case with samples collected prior to the pause of Spectrum 10K.

When the Data Access Committee approves a collaborator's request to access the Spectrum 10K data, the collaborator will only be able to access the data through a highly secure research database called a "repository". The data will remain secure, controlled by the Data Access Committee, and anonymised, so that the collaborator cannot identify participants from their samples or data. The collaborator will have to sign a formal and legally binding data transfer agreement



with the University of Cambridge, which will state explicitly what they can and cannot use the data for. They will not be able to copy or share the data further.

2. Will participants have access to their own data?

Participants will not have access to their own data. This is because under data protection legislation within the UK (UK GDPR and Data Protection Act 2018), specific exemptions are in place relating to data processing for scientific research and statistical purposes. This is to ensure the validity of the research that takes place. Data collected in Spectrum 10K is pseudonymised and research participants will not be identifiable from research results.

3. How is the information I give you kept confidential and anonymous?

Protecting the privacy of participants is our top priority. We will store personally identifiable information such as names, addresses, email addresses, and dates of birth separately from non-identifiable data such as saliva samples and medical data.

We will give non-identifiable data a unique ID in a process known as pseudonymisation. This means that researchers will not be able to identify individual participants from their samples or data while they carry out their research.

Only specific researchers in the team will have approval to access personally identifiable data. This will be limited to the Database Manager and one or two approved individuals for data management purposes. We will collect and use the minimum amount of personally identifiable data possible.

All the data will be stored securely and will be collected in line with the Data Protection Act 2018, the General Data Protection Regulations (GDPR), and the Common Law Duty of Confidentiality.

4. 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.