



This is what Spectrum 10K has said about:

Withdrawal from the study

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1. What happens to samples and data if somebody withdraws from the study?

Participants will be able to withdraw from the study, without giving any reason, by contacting info@Spectrum10K.org.

We modelled our withdrawal at three levels:

No Further Contact:

This means that Spectrum 10K would no longer contact you directly but would have permission to retain and use information and samples you provided previously and to obtain and use further information from your health records. This level of withdrawal allows researchers to study autism with the goal of improving the health of autistic people and their family members.

No Further Access:

This means that Spectrum 10K would no longer contact you or obtain further information from health records in the future, but still has permission to use the information and samples provided previously.

No Further Use:

In addition to no longer contacting you or obtaining further information, any information and samples collected previously would no longer be available to researchers. Spectrum 10K would destroy samples (although it may not be possible to trace all distributed sample remnants) and would only hold information for archival audit purposes. Such a withdrawal would prevent information about



you contributing to further research, but it would not be possible to remove data from research that had already taken place.

Going Forward

After further discussion, the Spectrum 10K team would like to propose simplifying this process by reducing the withdrawal levels to only one.

Should a participant wish to withdraw under the proposed simplified withdrawal process, they would be withdrawn at the level of “no further use”. All personally identifiable data would be deleted. We would retain non-identifiable data only for auditing purposes, so that we can ensure the validity of data analysis that has already taken place. This is essential for making sure that our research is reliable and accurate.

2. What will happen to Spectrum 10K data and samples after the project is finished?

After the project is finished, samples will be stored for 10 years, and data will be stored securely for 25 years. During this period, they may be shared with other researchers. After 25 years the data will be deleted.

3. What does it mean that Spectrum 10K is a re-contactable resource for all types of research (genetic or otherwise)?

By ‘re-contactable resource’, we mean that we may contact participants in Spectrum 10K to invite them to participate in other ethically approved studies as well. We may re-contact participants about any studies seeking to better understand co-occurring conditions and wellbeing in autism, whether or not those studies are primarily about genetics. Participants will be sent a maximum of 4 invitations per year.

Participants do not have to participate in other studies. They can decide when they receive an invitation to another study whether they would like to participate in that study or not.

We are open to discussion with the consultees about making this aspect of the study optional.