## Update on Spectrum 10K (September 10th 2021)

## An apology and an update

I am writing on behalf of the Spectrum 10K research team, including the co-lead researchers, to provide a further update regarding the study. From the feedback we have received from autistic people, their families, and charities we can see that we need much wider consultation, that we were not clear enough about the aims of the study, and that aspects of our study need further discussion. We apologise unreservedly for these issues and for any distress that they have caused.

## **Pausing to listen**

We have decided to pause any further recruitment of new participants into Spectrum 10K. We will also not analyse any data already collected in Spectrum 10K. This will give us time to co-design and conduct a meaningful consultation with autistic people and their families and incorporate suggestions for how to improve Spectrum 10K. This may take several months. Details of the consultation will be announced on our website.

Anyone who wishes to register their interest in Spectrum 10K during the pause will be able to do so <u>here</u>. We will not send out any new saliva kits until the consultation is complete. If you have received a saliva kit you can send us a saliva sample that we will store securely (without any genetic analysis) until the consultation is complete.

The University of Cambridge, the Wellcome Trust, and the Cambridgeshire & Peterborough NHS Foundation Trust (co-sponsor of the study) are all fully supportive of us pausing Spectrum 10K to undertake this listening. They recognise the study's scientific importance and that there has been no breach in the protocol as approved by the NHS research ethics committees. This pause reflects that we want to listen to and address concerns.

## Thank you

Thank you to those autistic people and their families who have shown their support for the study and continue to do so. We hope that together with autistic people and their families we can address the concerns.

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Simon Baron-Cohen on behalf of the Spectrum 10K team