We would like to invite autistic adults to participate in Phase 1 of a consultation we are running in relation to our autism research project, Spectrum 10K. Details are provided below.

**Who we are**

We are a research team based at the Autism Research Centre at the University of Cambridge. We recently launched an autism research study called Spectrum 10K, funded by the Wellcome Trust, which aims to explore the genetic and environmental factors contributing to autism, as well as frequently co-occurring health conditions. We believe that in the longer term, this research will lead to improvements in the health and wellbeing of autistic people. For more information, please visit: [www.spectrum10k.org](https://spectrum10k.org/)

**What has happened since the launch**

After we launched the project, thousands of people registered at our website to participate. We also received a large number of messages of concern. Some of the concerns were about:

* not having consulted with enough autistic people
* the purposes of the study not being clear
* what the participants are told about the study
* the potential for autism genetics research to inadvertently lead to a prenatal screening test and therefore prevention of births of autistic babies (sometimes referred to as eugenics)
* the belief that the research team supports the idea of prenatal screening for autism

We have apologised for any distress that we have caused. We have decided to pause the study to co-design and conduct a detailed consultation with autistic people and other stakeholders and incorporate suggestions for how to improve Spectrum 10K.

**The consultation**

We recognise that we need much wider consultation, and that aspects of the study need further discussion.

So far, the wider consultation plan has been planned in three phases:

* ​Phase 1 – working with approximately 15-20 autistic people (and some parents/carers) to decide who should be involved in co-designing the consultation. *Note that since announcing this we have received suggestions to include more people and are acting on this.*
* P​hase 2 – co-designing the consultation with the group agreed in phase 1, ensuring that autistic people are consulted from a wide range of backgrounds.
* ​Phase 3 – running the consultation.

After the consultation we will review the discussions that have taken place and make changes to the study where appropriate, before restarting the study.

The exact content of these phases will depend on the consultation process. We cannot say now what this will entail until we hear what the autism community has to say.

**An invitation**

We are currently in Phase 1. We are working with an independent organisation called Hopkins Van Mil to facilitate group discussions to decide who should be involved in Phase 2, co-designing the consultation.

Among other groups, we are inviting a number of autistic adults to be involved in Phase 1 and would like to invite you to participate.

If you choose to take part, you will be invited to join one Zoom video call with one or two members of the Hopkins Van Mil team and up to five other autistic adults. This will take place on the 24th of January at 9:00-11:00am. Participation will be confidential, and all attendees will be reimbursed for their time at a rate of £20 per hour.

If you are interested, please email Hopkins Van Mil at [info@hopkinsvanmil.co.uk](mailto:info@hopkinsvanmil.co.uk) to let us know, by the 21st of January. They will then follow up with more information and to coordinate dates and times.

We look forward to hearing from you.

Best wishes,

The Spectrum 10K Team