



This is what Spectrum 10K has said about:

Researchers

1. Who is involved in Spectrum 10K and in what capacity?

The Spectrum 10K research is being led by a team from the Autism Research Centre (ARC), which is part of the University of Cambridge.

The Principal Investigator (PI) for Spectrum 10K is Professor Simon Baron-Cohen, who is the Director of the ARC. As the PI Simon oversees and is responsible for all aspects of Spectrum 10K, including overseeing and directing the studies design and scientific integrity.

The team also includes four Co-Principal Investigators (Co-PIs) from the Wellcome Sanger Institute, which is a research institute in the United Kingdom, and from the University of California Los Angeles (UCLA), which is a public university in the United States. Professor Simon Baron-Cohen and the Co-PIs share responsibility for data analysis and the scientific integrity of the project.

The Co-Principal Investigators are:

Professor Daniel Geschwind, who is the Gordon and Virginia MacDonald Distinguished Professor of Human Genetics, Neurology and Psychiatry at UCLA.

Professor Matthew Hurles, who is the Head of Human Genetics at the Wellcome Sanger Institute.

Professor Hillary Martin, who is a Group Leader at the Wellcome Sanger Institute.

Professor David Rowitch, who is the Head of Paediatrics at the University of Cambridge.

The Spectrum 10K team also involves the Director of Research Strategy, study co-ordinators, a post-doctoral researcher, and a data manager – all based at the ARC.

For more information about the research team, visit spectrum10k.org/our-team/.

Spectrum 10K is sponsored by the University of Cambridge and by the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). The sponsors take overall, legal responsibility for ensuring that Spectrum 10K is set up, runs, and reports appropriately.

Spectrum 10K is also working with 18 NHS Trusts across the UK. The role of these Trusts is to help identify people who would like to participate in Spectrum 10K and to help them register for the study.



2. Is Autism Speaks involved in Spectrum 10K?

Autism Speaks is not involved in Spectrum 10K. Autism Speaks is not providing any of the funding for the project. We have not discussed the project with Autism Speaks at any point.

During Spectrum 10K, we plan to analyse previously collected genetic data from several other databases. One of the databases that we plan to use is the Autism Genetic Resource Exchange (AGRE), which is owned by Autism Speaks. We will have to apply to Autism Speaks for approval to access AGRE and pay a small fee to Autism Speaks for each piece of data that we access. This will not enable Autism Speaks to influence Spectrum 10K in any way other than approving or denying our application. For more information about the process for accessing AGRE, visit <https://www.autismspeaks.org/applying-access-agre-data-and-biomaterials>.

Some members of the research team have an indirect relationship with Autism Speaks. The ARC and the Spectrum 10K PI, Simon Baron-Cohen, are involved in AIMS-2-TRIALS, which is a research project being carried out by 48 European organisations. Whilst AIMS-2-TRIALS is primarily funded by the European Union, it receives some of its funding from Autism Speaks. Spectrum 10K is not directly involved with AIMS-2-TRIALS in any way. For more information about Autism Speaks' role in AIMS-2-TRIALS, visit

<https://www.aims-2-trials.eu/about-aims-2-trials/team/autism-speaks/>. In addition, in 2010 one graduate student at the ARC was funded by a predoctoral fellowship investigating 'Hypersensitivity in autism: a psychophysiological and neuroscientific approach', which was funded by Autism Speaks. The fellowship ended in 2012 and the ARC has received no direct funding from Autism Speaks since then.

3. What was Daniel Geschwind's role in Cure Autism Now (which later became Autism Speaks)?

In the 1990s Professor Daniel Geschwind chaired Cure Autism Now's (CAN) scientific advisory board as a neurologist.

Cure Autism Now was created by parents in the autism community in the 1990s to fund autism research, primarily for syndromic forms of autism (autism with a known genetic cause, such as Fragile X syndrome and Tuberous Sclerosis Complex), at a time when there was almost no funding.

Daniel Geschwind's research was never funded by CAN. He did not receive money from CAN for his involvement.

Daniel Geschwind shares the values of the rest of the Spectrum 10K team. He acknowledges that language, concepts and priorities of the autism community have changed over the past 30 years.



26. Has the ARC ever received funding from Cure Autism Now?

The Autism Research Centre received a grant for approximately £50,000 from Cure Autism Now (CAN) in 2002. An example of research funded by this grant is this functional MRI study looking at cognition in autistic people. A further grant for approximately £62,000 funded by Cure Autism Now, 'The role of perceptual attentional disturbances in the early diagnosis of autism', ended in 2008. At the time of receiving CAN funding, CAN was one of the few funding bodies available in the UK.

2. Who is running the consultation?

The Spectrum 10K consultation is being co-led by Hopkins Van Mil, which is an independent agency; by Leneh Buckle, who is an autistic researcher working on a freelance basis for Hopkins Van Mil; and by the Spectrum 10K team based at the ARC.