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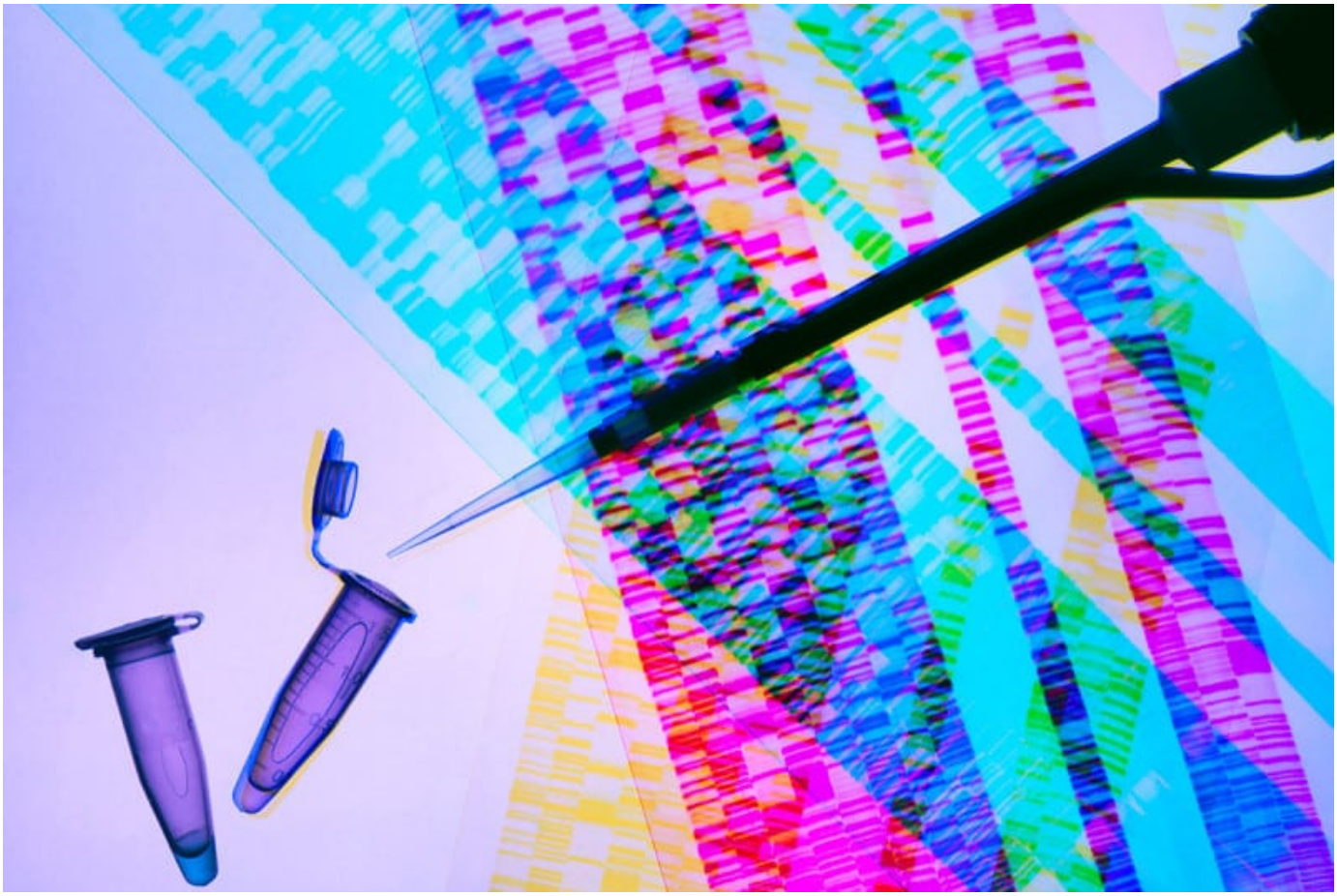
# Genetic studies intend to help people with autism, not wipe them out

There are fears genetics research into autism will lead to eugenics and eradication of the condition. That must never come to pass, says **Simon Baron-Cohen**



**Genetic studies involving ten of thousands of people could expand our knowledge on many conditions**
Andrew Brookes/Getty

By **Simon Baron-Cohen**

Genetics plays a large role in causing autism, so knowing more about which genes influence it could allow a better understanding of the condition.

It is a rapidly unfolding area of research, but there is a problem. As director of the University of Cambridge's Autism Research Centre, I am increasingly aware that more and more autistic people don't want to take part in genetics studies.

It seems to be happening because of a fear that the agenda is eugenics – find the genes to identify potentially autistic babies in pregnancy, and terminate such pregnancies. These fears are

understandable if we look at how this has happened in the case of Down's syndrome.

Some people also worry that genetics research will lead to genetic engineering to "normalise" autistic people. Again, I would be horrified at this application of science, because it doesn't respect that people with autism are neurologically different, and like any other kinds of diversity (such as hair, skin or eye colour, handedness, or sexual orientation) should be accepted for who they are.

## Opposed to eugenics

My colleagues and I are opposed to any form of eugenics. The worry though is that if people equate autism genetics with a eugenics agenda, valuable progress on autism genetics could be slowed down.

Today, autism is known to be strongly genetic, with heritability estimated at between 60 and 90 per cent. Autism is not 100 per cent genetic – if one identical twin has autism their co-twin doesn't always have it. The obvious conclusion is that a genetic predisposition interacts with environmental factors.



Since the start of this century – only 18 years ago – 100 "high confidence" genes have been associated with autism. They are called high confidence because they have been identified in multiple labs. These include single rare gene mutations that are sufficient to cause autism, but are found in less than 5 per cent of autistic people.

We now estimate that the 100 that have been found are just the tip of the iceberg, and that between 400 and 1000 genes may be involved in autism.

Furthermore, we now think that at least 50 per cent of the heritability of autism may be due not to rare mutations but to common genetic variants that we all carry, with some versions occurring in different frequencies in autistic people.

To identify common genetic variants requires many tens of thousands of people to take part in studies. For example, we worked with consumer DNA testing company 23andMe recently and discovered several common genetic variants by asking 80,000 people who had sent samples to the company to

take an online test. It will take years of collaborative effort to collect this "big data" to discover all the genes relevant to autism.

A large part of that collaboration is with the autism community. If that community loses faith in this research, then progress will slow down. And it won't just be science labs that are affected.

As scientists, our agenda is simply to understand the causes of autism. This has intrinsic value, because it contributes to human knowledge and will hopefully deepen autistic people's understanding of their own identity.

## Help where desired

Genetic knowledge could also change lives for the better. For example, one clinical use of gene discovery that we think is ethical would be early detection of autism, with a view to early intervention, if parents opt for this.

This isn't at odds with the "neurodiversity" view, because in an ideal world early interventions would target only symptoms that cause disability or distress, not autism itself. Examples of unwanted symptoms might be language delay, epilepsy, learning difficulties or gastro-intestinal disorder.

Another advantage of early detection might be better early support for children who are vulnerable to becoming teenagers with poor mental health. If you leave an autistic child without the right support and they are expected to cope in an education system that might not fit their learning style, or if they are bullied for being different, you end up with a child who feels like they are failing. Or a child who loses self-confidence because they are abused and manipulated by others with more "street smarts".

We at the Autism Research Centre have no desire to cure, prevent or eradicate autism. I hope the autism community will be willing to trust researchers who nail their colours to the mast in this way.

Autistic people have a special mix of strengths and challenges. The strengths include excellent attention to detail, memory for detail, pattern recognition and honesty. Our aim, as clinicians as well as scientists, is to make the world a more comfortable place for autistic (and all) people to live in.

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***Simon Baron-Cohen*** *is professor of developmental cognitive neuroscience at the University of Cambridge, UK. He and his team are currently inviting participants to join their study investigating the possible genetic links between mathematical ability and autism (http://dna.autismresearchcentre.net), funded by the Templeton World Charity Foundation and the Autism Research Trust*

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