



The Spectrum 10K study aims to collect DNA from 10,000 autistic people and their families.

# HIGH-PROFILE AUTISM GENETICS PROJECT PAUSED AMID BACKLASH

Study aimed at collecting DNA from 10,000 autistic people and their families has drawn criticism.

By Katharine Sanderson

**A** large, UK-based study of genetics and autism spectrum disorder (ASD) has been suspended, following criticism that it failed to properly consult the autism community about the goals of the research. Concerns about the study include fears that its data could potentially be misused by other researchers seeking to ‘cure’ or eradicate ASD.

The Spectrum 10K study is led by Simon Baron-Cohen, director of the Autism Research Centre (ARC) at the University of Cambridge, UK. The £3-million (US\$4-million) project, which is funded by the London-based biomedical research charity Wellcome, is the largest genetic study of ASD in the United Kingdom. It aims to collect DNA samples, together with information on participants’ mental and physical health, from 10,000 autistic people and their families. This will be used to study the genetic and environmental contributions to ASD, and to co-occurring conditions such as epilepsy and gut-health problems. “If we can understand why these co-occurring

conditions are more frequent in autistic people, that could open the door to treatment or management of very distressing symptoms,” says Baron-Cohen.

But soon after the study’s high-profile launch on 24 August, some autistic people and ASD researchers expressed concern that

**“There is a real need for a broader discussion between autistic people and their families, and researchers.”**

it had gone ahead without meaningfully consulting the autism community. Fears about the sharing of genetic data and an alleged failure to properly explain the benefits of the research have been raised by a group called Boycott Spectrum 10K, which is led by autistic people. The group plans to protest outside the ARC premises in Cambridge this month. A separate petition against the study gathered more than 5,000 signatures.

Damian Milton, a researcher in intellectual

and developmental disabilities at the University of Kent in Canterbury, UK, is one of those who signed the Boycott Spectrum 10K petition. Milton has been diagnosed with Asperger’s syndrome, a form of ASD. He says it is not clear how the study will improve participants’ well-being, and its “aim seems to be more about collecting DNA samples and data sharing”.

As a result of the backlash, the Spectrum 10K team paused the study on 10 September, apologized for causing distress, and promised a deeper consultation with autistic people and their families.

## Screening fears

Even before Spectrum 10K launched, some autistic people were uncomfortable with aspects of Baron-Cohen’s research. He developed and popularized the controversial ‘extreme male brain’ theory of ASD, which is based on the idea that, on average, males are better than females at ‘systematizing’ – recognizing patterns, and sticking to rules – whereas females are better at empathizing. Behaviour seen in autistic people, Baron-Cohen asserts, sits firmly at the male end of this continuum.

“I think Simon has made some really prominent contributions to autism theory,” says Sue Fletcher-Watson, a psychologist at the University of Edinburgh, UK, who studies ASD. But “there’s a component of suggesting that autistic people don’t have empathy”, she says. “That has been extremely damaging and stigmatizing for autistic people, and is very much at odds with many autistic people’s lived experience, which is often a sort of uncontrollable excess of empathy.”

The antipathy towards these theories is now overlaid by concerns about the genetic research planned by Spectrum 10K, and how the study will share its data. Many funding bodies, including Wellcome, mandate that researchers make their results freely available. But critics of Spectrum 10K want assurances that the genetic data will not be misused by researchers, and fear that this open-access policy means the project cannot guarantee that this won’t happen.

Kieran Rose, an advocate for autistic people and a member of Boycott Spectrum 10K, says he is worried that the research could lead to a prenatal screening test for ASD or related conditions. “A genetic study would be terrifying for lots of autistic people; there’s a long-established and well-known history around eugenics and disability,” adds Fletcher-Watson.

The Spectrum 10K website states that it “does not aim to eradicate autism”. Baron-Cohen says that his team is vehemently against eugenics, and that prenatal screening is out of the question. “Genetics of autism is complex; we may be talking about hundreds or thousands of genes,” he says. “You could

never diagnose autism prenatally, and that's because, even if we knew the biology, diagnosis rests on behaviour. That's only possible to observe postnatally."

### Consultation controversy

Some in the autism community are also frustrated that they were not consulted by Spectrum 10K about the kind of research that would best serve autistic people. Autistica, a London-based ASD charity, initially lent its support to the study, but subsequently asked the Spectrum 10K team to remove its endorsement from study material. "There is a real need for a broader discussion between autistic people and their families, and researchers," says James Cusack, Autistica's chief executive.

To address these misgivings, the Spectrum 10K team is now planning a consultation with hundreds of autistic people and their families, and intends to create a representative committee to oversee the project's data-sharing strategy. "If there are ethical reasons for

limiting who can access the data, that's fine, you can put those constraints in place," Baron-Cohen says.

In a statement, a Wellcome spokesperson said: "We are fully supportive of the researchers' plans to pause and undertake further engagement work, consistent with inclusive research principles."

The pause could last several months. Meanwhile, the Health Research Authority (HRA), a UK regulator of health and social-care research, is investigating several unspecified concerns about Spectrum 10K's ethics approval. That investigation might take several weeks, and Spectrum 10K cannot restart without the HRA's permission, says Eve Hart, the authority's head of communications.

"I do think a research team with this level of experience in autism research should have seen this coming," says Fletcher-Watson. "They should have done more groundwork to engage with the community and prevent the distress that's been caused, and to design a study that would serve the community's needs."

at US colleges. "We want to make sure this stays in the public eye until he is reinstated."

*Nature* contacted Hu's lawyer, Phil Lomonaco, but Hu declined to comment.

UT Knoxville provost John Zomchick also declined to comment on Hu's possible return, saying that he was not able to speak about personnel matters. "We're communicating with his attorney, and we're following the processes we would follow in any case," he says.

### Foreign ties

Over the past few years, US science agencies have increased their scrutiny of scientists who receive US research money but who also have foreign ties or get financial support from other countries. Science agencies require that foreign money or positions, such as professorships, be disclosed on grant applications. Also, NASA is prohibited from funding people involved in certain collaborations in China. However, university groups have said that existing disclosure rules supplied by US agencies are difficult to interpret.

This focus on foreign ties intensified after the Trump administration began its 'China Initiative' in 2018, with the aim of rooting out trade theft by foreign spies at US companies and enterprises. Since then, the US Department of Justice has accused a number of researchers of concealing from the US government foreign links or sources of foreign funding, most often related to China.

Hu was arrested in 2020 and accused of wire fraud and making false statements to the government. After that, UT Knoxville suspended him without pay. Hu is a Canadian citizen; following his suspension, his US work authorization expired, so the university terminated his position.

This sequence of events has been one point of concern among faculty members. Another is that the faculty handbook says professors who are indicted on felony charges "may" be suspended. So they are questioning whether the university needs to pursue that route before a case goes to trial. "There is no presumption of innocence," says Lou Gross, president of the faculty senate.

"Personally, I'm kind of appalled with the way a colleague was treated," says Gross. Also, according to the faculty handbook, the university administration must consult the faculty senate president before suspending a faculty member. Gross says this consultation did not take place in Hu's case. Zomchick disagrees, and says the university's then-provost did call the faculty senate president about the case. "That's a judgement call about whether you consider something information or consultation," he says.

Hu's trial began in June, and ended in a mistrial days later, after the jury could not reach a verdict. Lomonaco had argued that the rules regarding NASA funding and affiliations with

# UNIVERSITY UNDER PRESSURE TO REHIRE ACQUITTED SCIENTIST

Faculty members say Anming Hu, cleared of charges that he hid links to China, should get his job back.

By Nidhi Subbaraman

**F**aculty leaders at the University of Tennessee (UT), Knoxville, are mounting a campaign to rehire a nanotechnology researcher who lost his job after the US government accused him of hiding his links to a university in China.

Anming Hu, formerly a tenured professor, was acquitted of the charges by a judge on 9 September.

The case is part of US efforts, escalated under former president Donald Trump, to find spies working at US universities and prevent them from sharing intellectual property with China. Hu was the first scientist in the United States whose case went to trial in the past few years because of claims related to foreign ties. His situation demonstrates the far-reaching consequences for individual researchers who get caught up in the US crackdown, advocates say.

At UT Knoxville, Hu's backers are calling for the university to return him to his position, with back pay. The university suspended him after the US Department of Justice accused him of concealing an appointment with the

Beijing University of Technology while receiving funding from NASA. His employment at the university was later terminated.

University officials have been tight-lipped on the next steps in Hu's case, which has frustrated faculty members. The case has also prompted a broader discussion about how the university responds to requests from law-en-

**"People are pushing back at the faculty-member level, and I think that's important."**

forcement agencies about faculty scientists, and ignited a call for transparency overall.

"The faculty are paying a lot more attention, and the faculty are demanding to know why he's not being reinstated," says Mary McAlpin, a French studies specialist at UT Knoxville who has argued for Hu's rehiring in her role as president of the university chapter of the American Association of University Professors (AAUP), an organization for faculty members