

This is the plain language summary for a letter written by lots of Autistic people who are upset about a new study called Spectrum 10K, which was talked about for the first time on the news and social media on Tuesday 24th August 2021.

This letter - also called a statement - is about why we are upset about this new study, and we want as many Autistic people and their friends and family to read why we are upset. If people agree that this study sounds wrong and believe like we do that it is not a good or safe study for Autistic people, then we are asking people who are able to, to sign our statement (letter) to say they agree with us, and to show they support us asking for the study to be changed or even stopped from happening.

The full statement (letter) including where you can sign if you say you agree with our statement can be found [HERE](#)

There is a dedicated @BoycottSpect10K account on Twitter, and you can find Autistic people discussing the study via the hashtag #StopSpectrum10K

BACKGROUND:

Lots of people, including Autistic professionals and the public, are worried about the ethics (how moral or right something is for humans) of a new study that has not been clear about how it will help Autistic people.

Lots of Autistic people, and Autistic professionals, and the public want good studies to be done that will help Autistic people with things they struggle with, and things that mean they have poor wellbeing.

Lots of people are worried that this new research study will not do this because the people in charge of the study have not been clear about what the study is doing, and we want them to be clearer and not lie or hide information.

We want the study to be very clear, with simple language, about how Autistic people giving them saliva (spit) will be used to improve Autistic people's lives. We also want them to be clear about who they will be giving the information to

in the future in case we do not trust the people they want to give our information to.

CONSENT:

A study information and consent form is a typed or written letter that explains what researchers are asking people to do in their study. If the researchers are very clear about what they are doing in their study, then people can agree (called consent) to take part in the study and do the things the researchers are asking them to do.

For this study we think the researchers have not been clear about the reasons and aims of their study, which is like hiding or lying about what they are actually doing, and they have used different words that mean different things, which confuses people. When people are confused and not told things clearly, they cannot agree to the study as they do not have all the information or facts about it.

Lots of Autistic professionals and the public have looked at the typed and written information from the researchers of this study and do not think it sounds safe for Autistic people to take part.

STEERING COMMITTEE NOT FORMED:

We have not been told who makes the decisions to give researchers we do not know the saliva (spit) information Autistic people might give them for this study. People cannot consent (agree) to take part in this study because the study people are saying it will give researchers we do not know in the future our saliva (spit) information.

We have not been told who is in charge of making decisions for this study (called a steering committee because they are supposed to steer decisions and choices for what to do), and so we cannot know what the study people think Autistic people care about. They might think we want something that we do not want, and they might want things that actually end up hurting Autistic people, or even meaning that Autistic people are not born in the future.

FEARS AROUND EUGENICS AND INTERVENTIONS:

Autistic people are worried that even though S10K (the short name for the Spectrum 10K study) say they are against eugenics (science that tries to control

the human population by getting rid of certain people/features they decide they don't want) and are focused on the well-being of Autistic people, we feel like we are being lied to because when we look at what they have said or written more closely, there is nothing about helping Autistic people and their wellbeing.

What they have written about is finding the cause of autism and why Autistic people are born Autistic. They have already collected a very large number (90,000) of Autistic people's DNA (DNA is small, invisible information inside our bodies), and so we don't understand why they need 10,000 more Autistic people and their DNA information, but we do know that DNA information is very valuable.

The project people are telling us that the DNA information will be used for other studies and by businesses in the future, but we do not know who will use our valuable and important DNA information in the future. We also don't know if our DNA information will be used to make an autism test that pregnant people can use so that they can decide not to have an Autistic baby. This has happened for another group of people who have something called Down Syndrome, and it has meant that lots of these people have not been born. We are scared this will happen to Autistic people too, and we don't want Autistic people to stop being born.

HURTFUL LANGUAGE AND IDEAS ABOUT AUTISTIC PEOPLE:

Autistic people do not trust the people leading this project because they have publicly said some very worrying things about Autistic people in the past. They have said things like Autistic people are not human.

CONCERNS ABOUT THOSE LEADING THE PROJECT:

The men leading the S10K project have a very poor history and attitude towards Autistic people. The work they have done has caused lots of damage and hurt to Autistic people. We believe they do not understand Autistic experience or want to work with Autistic people to understand Autistic experience, but are focused on "curing autism" and/or stopping Autistic people being born.

NOT WORKING WITH AUTISTIC PEOPLE:

S10K do not have enough Autistic people guiding the project. They said they will only consider Autistic people in 6 months' time when people have given their DNA information to them already. This means that they are picking people who have a good opinion of S10Ks work so it is not fair or balanced. Simon Baron-Cohen is very important in Autism research and a group he is in recently published guides about including Autistic people and what they want in all research, but the S10K project that he co-leads does not do that.

QUALITY OF LIFE:

S10K have not told us what they mean by Autistic quality of life and wellbeing, or who is deciding this, but we do know it is not Autistic people making the decision or even being asked.

S10K already know what contributes to poor Autistic mental health and wellbeing and this information is not in our DNA. Autistic people know that environment (people, places, things, life experiences, surroundings, abuse, poor support systems, etc.) are the main issues for mental health and wellbeing.

IGNORING RECENT RESEARCH AND THE AUTISTIC COMMUNITY PRIORITIES AND CONCERNS:

S10K are saying they want to investigate co-occurring conditions that some Autistic people have, like epilepsy, but they only want DNA from Autistic people and their relatives, not from non-autistic people who also experience epilepsy. This makes us feel like they are not telling the truth. But if they are looking for the cause or to cure autism then what they are saying would make sense, but as we've explained, if they are looking for Autism in our DNA information in our bodies this not what Autistic people want.

SUBTYPES AND SUBGROUPS:

Subgroups (putting people into different groups) are harmful to Autistic people and are not correct. Scientists have been trying to use subgroups since autism was first talked about and it has not worked. Once we removed subgroups much more learning has happened in understanding Autistic experience. We believe Simon Baron-Cohen wants to bring back subgroups as a lot of his old work is based on this even though it's not helpful to Autistic people. We don't want Autistic people grouped based on whether other people think they are useful or

not useful. We do not want to split up the community because each Autistic person is totally unique and valued.

AMBASSADORS:

We think S10K are using famous people to trick people into thinking that they are safe, and that we should trust them. Some of the ambassadors (people promoting the S10k project) haven't been very nice to people who have asked them questions about the project, and they have all recently stopped talking about the project. The ambassadors are not very knowledgeable about the S10K project, so we don't trust them.

When the study people went on television to talk about their project, they didn't invite Autistic people to hear what they thought of their ideas, and when they did invite an Autistic person on the radio, they did not let them speak and ask their questions about the project and their worries about it.

CONCLUSION:

We are very, very worried. Everything that has been talked about or written about this project is confusing and not clear. We don't see how this can be a good study that will help Autistic people when it's so confusing and doesn't involve enough Autistic people. We haven't been asked if we want this study done or how we feel about it.

We think this study got money by saying one thing, but it looks like they are doing something else with it. This feels like lying.

We're worried that our spit (which contains our valuable, invisible DNA information that researchers can see with special equipment) could be used to hurt Autistic people or stop Autistic people being born in the future.

We feel like S10K do not understand Autistic people and that they want to sell the information they get from our spit.

We do not support this study and we will tell people why and hope that they will also not support or take part in the study.

DEMANDS AND WHAT WE WANT TO HAPPEN NEXT:

We are asking that some other people look at this study to make sure there is no lying or hiding things from the public and that it is not dangerous to Autistic people either now or in the future.

We also want to see the paperwork and files that tell us what this study is actually about because S10K are not being clear or making a lot of sense.

If you think you understand why we are worried about this study, and agree that people should check whether it is a good study or a bad study that might hurt Autistic people than please sign our full statement letter, which you can find [here](#)