Joint statement from Autistic community members, academics, representatives of advocacy organisations, and allies about grave concerns regarding the Spectrum 10K study announced Tuesday 24th August 2021 (**document includes plain language summaries for accessibility and uses a font easier to read for some people. The plain language summaries can be found on their own for those who need them HERE. There is a dedicated @BoycottSpect10K account on Twitter, and you can find Autistic people discussing the study via the #StopSpectrum10K**).

BACKGROUND:

On the 24th of August 2021 with a blaze of obviously well-planned publicity, the Spectrum 10k (S10K) research project was announced.

The project arrived with endorsements from 'celebrities' related to the autism narrative such as Autistic Naturalist, Chris Packham; parent Paddy McGuiness; parent TV presenters and singing coaches Carrie and David Grant who are parents of Autistic children; along with a selection of professionals from a variety of different fields that work with Autistic people.

It also came with several named Autistic 'ambassadors' whose role it is to publicly promote and endorse the project.

There was a general backlash from a significant number of the Autistic community and allies via social media, including the general population, the Advocacy community, Advocacy groups and organisations, academics, professionals and parents, and this joint statement intends to declare the concerns and position of the signatories (signatures will continue to be collected following submission of this statement to Health Research Authority).

PLAIN LANGUAGE SUMMARY: 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.

PREFACE:

We are collectively gravely concerned about the Spectrum 10k research project.

We fundamentally recognise the need for good, robust genetic and biological research in order to aid greater understanding of the impact of conditions that have genetic roots and can have life-limiting effects or impact on the well-being of Autistic people.

However, we have grave issues over how the data from genetic research could be used, and the very obvious lack of safeguards for its future use.

We have concerns over the vulnerability and naivety of those who will give their samples to this project, or do so on behalf of others, without understanding the implications of DNA collection, genetic research and the narratives around it, or the histories and agendas of those leading and organising this research.

We have concerns over the research itself, the manner in which the research has been created, the process of how the research has been launched and publicised, the lack of clear information and evidenced robust aims and objectives, and the implications of this research.

PLAIN LANGUAGE SUMMARY: 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.

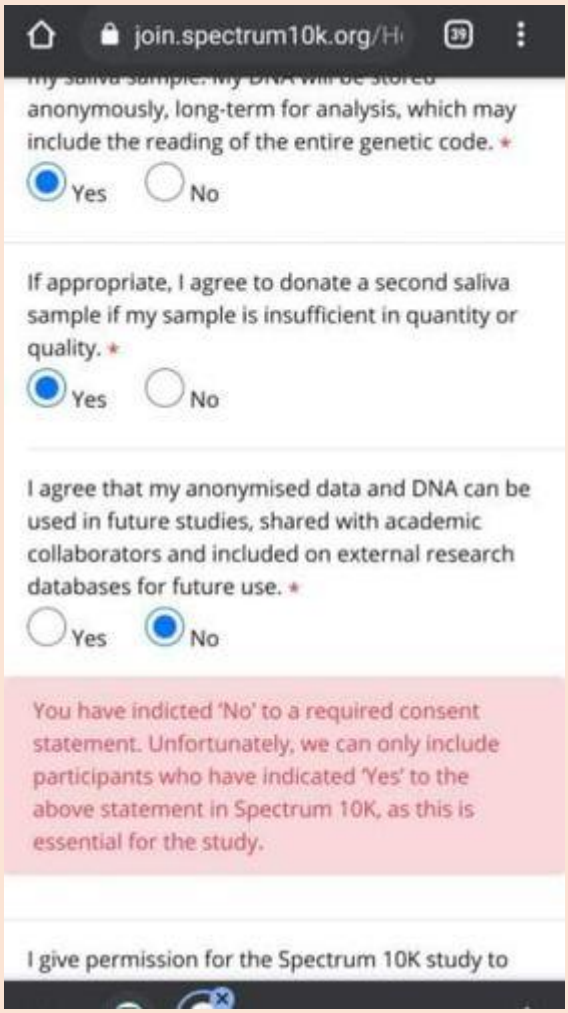
SUMMARY OF KEY CONCERNS LAID OUT IN DETAIL IN THE REMAINDER OF THIS STATEMENT:

1. **Lack of transparency**. There is a disconnect between what the study is telling the public and what they received funding for.
2. **Biodata regulations**. We expect to see clear information about what the regulations around biodata are, its use, and future use once the main study is completed.
3. **Consent issues**. With the lack of transparency and clarity about what the study is, what it will do, how it will do it, and what it will do with the genetic data, no potential participant can provide sufficiently informed consent. Further, why could the use of DNA data by others not have been an optional consent clause?
4. **Suitability of the principal and co-investigators**. Based on their track records, we seriously call into question the suitability of the principal and co-investigators.
5. **Conflicts of interest.** Key researchers did not disclose publicly any and all conflicts of interest to potential participants, or that there are current plans for this dataset to be combined with other datasets based on the Common Variant Genetics of Autism and Autistic Traits (GWAS) Consortium grant.
6. **Ethical issues.** We want to know any and all ethical issues that were discussed in the ethical review of this study.
7. **Ethical issues and transparency.** Given the disparities between what this study was awarded funding for, and what they are telling the public and, on the information and consent forms, we expect to be told if there was a substantial amendment submitted by the study.

CONSENT:

There are a number of concerns regarding the study's attempts to obtain participant consent. The gravest concern is the inability to contribute a DNA

sample without the DNA information being passed on to any outside or connected further parties.



ALT TEXT: Screenshot of part of the S10K consent form, the relevant section reads:

"I agree that my anonymised data and DNA can be used in future studies, shared with academic collaborators and included on external research databases for future use*". Where this example screenshot selected that "no" they do not consent to these conditions there is a red warning pop up that reads:

"You have [indicated] 'No' to a required consent statement. Unfortunately, we can only include participants who have indicated 'Yes' to the above statement in Spectrum 10K, as this is essential for the study." ALT TEXT ENDS.

S10K are promoting this study as one looking for genetic links to autism and the (vague) wellbeing of Autistic people, and so it is a glaring red flag that vulnerable Autistic people will be handing over their DNA information that can be used by further parties (more on this concern throughout this statement). Why could the use of DNA data by others not have been an optional consent clause?

Further consent issues: the consent forms for this project are contradictory and confusing and risk leaving vulnerable people exposed to signing up to something they are unable to fully understand because it has not been explained clearly enough.

Consent for S10K is sought for DNA collection, data collection, and complete access to medical records without clear description as to what the project aims to do; how any of this data will be used by the project; who that data will be passed onto in the future; or how it will be used in the future. We fear that there are grounds for data use violations here, particularly if the DNA data is passed onto organisations in countries outside of the UK.

Some examples of the confusing and contradictory statements include:

You can stop participating at any time, "but we will keep information about you that we already have," although later in the form, it says you can withdraw your data under "No Further Use" and "would only hold information for archival or audit purpose".

It is unclear whether that means they are deleting any of the information, and what "information" means in this context.

Further, multiple different words are used without defining them, and are used interchangeably at different places throughout the consent form, including "samples," "DNA," "information," and "data".

The S10K consent form states that if participants withdraw with "No Further Use" that they will destroy the "samples", but this statement is unclear about whether this includes DNA data that was put into the dataset on a computer, or only the original saliva sample/s.

The ‘easy-read’ version of the project description (designed for those whose cognitive differences and learning styles might not suit wordy documents and academic language) is not easy-read at all. There are numerous guidelines on the use of and creation of easy-read explanations, yet these do not appear to have been adhered to at all. This ‘easy-read’ document includes generic pictures, pictures with little or no explanation, and very vague statements. The document does not clearly explain the purpose of the project aside from a vague ‘we are doing this to help’, and does not explain what DNA or genetics are, or make any attempt to explain the possible implications of contributing biodata.

These are huge practical and ethical issues, which should be basic for any study, let alone a study as large and as significantly funded as this.

It is imperative that the consent forms and descriptions of the project are clear because the researchers are asking for information from a vulnerable, marginalized group with legal protected characteristics. Some Autistic people may need information communicated differently, more specific details, or different descriptions than might non-autistic participants. This risks leaving vulnerable people exposed to signing up to something they are unable to fully understand because it has not been explained clearly enough.

Due to the consent forms being contradictory and confusing, and the vague and unclear purpose of this study, consent itself is an issue, no matter how well it is obtained.

Further, the project is encouraging parents and carers to sign over DNA samples of children and adults who cannot consent for themselves, encouraging Autistic people to give their DNA and complete medical records, yet important information is either intentionally or unintentionally obfuscated (unclear; obscured), or just simply not given. **Children and vulnerable adults would have their DNA information handed over to this study by parents and/or carers, but due to the studies insistence on data sharing once the study is complete, this would be a lifelong commitment that children would have no control over, and they would have no comprehension of this lifelong commitment or the possible implications of how their biodata could be used in the future.**

Academics from various scientific backgrounds including genetics and autism research have commented that the consent form, descriptions, and easy-read document are misleading, unclear, do not describe the project's purpose or methodology in any way and are not fit for purpose. They have said clearly that the S10K study as publicised would not have passed an ethics committee.

PLAIN LANGUAGE SUMMARY: 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.

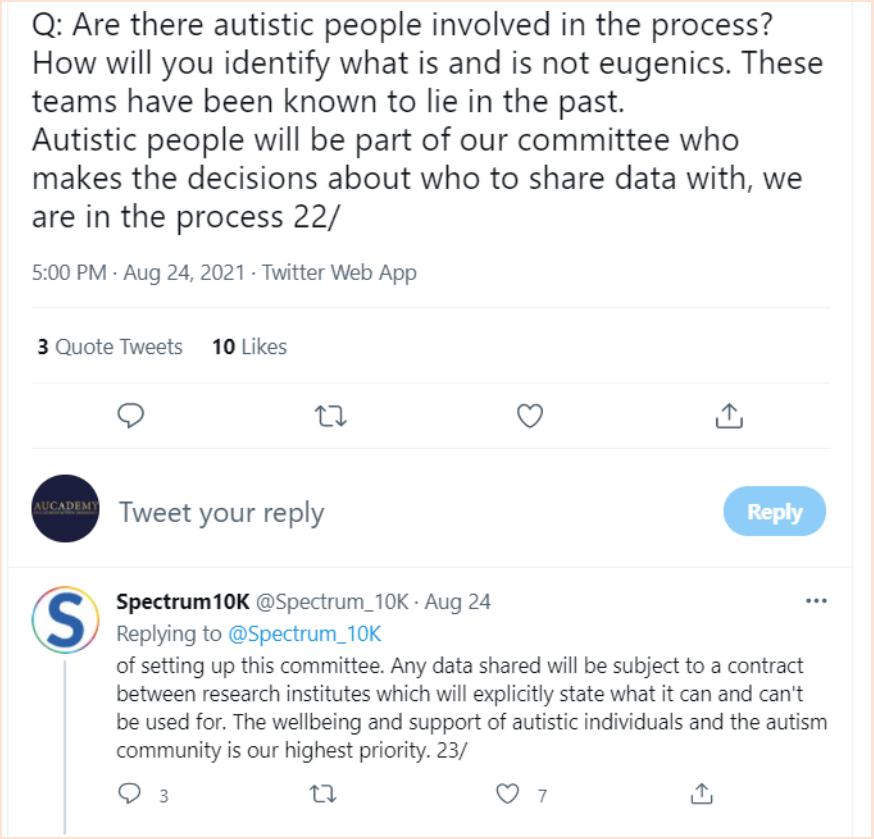
For this study we think the researchers have not been clear about the reasons and aims of their study, which is like hiding or lying about what they are actually doing, and they have used different words that mean different things, which confuses people. When people are confused and not told things clearly,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

Lots of the following taken from S10K website and Twitter:
https://docs.autismresearchcentre.com/Spectrum10K/Spectrum10K_FAQs.pdf

STEERING COMMITTEE NOT FORMED:

The Steering Committee for this research project currently has not been formed, and the study's social media said it is "in the process" of being set up (Reference: https://twitter.com/Spectrum_10K/status/1430198220244783105?s=20 - SEE PICTURE BELOW WITH ALT TEXT).



ALT TEXT: Screenshot of Spectrum10K @Spectrum_10K tweet: Aug 24, reads:

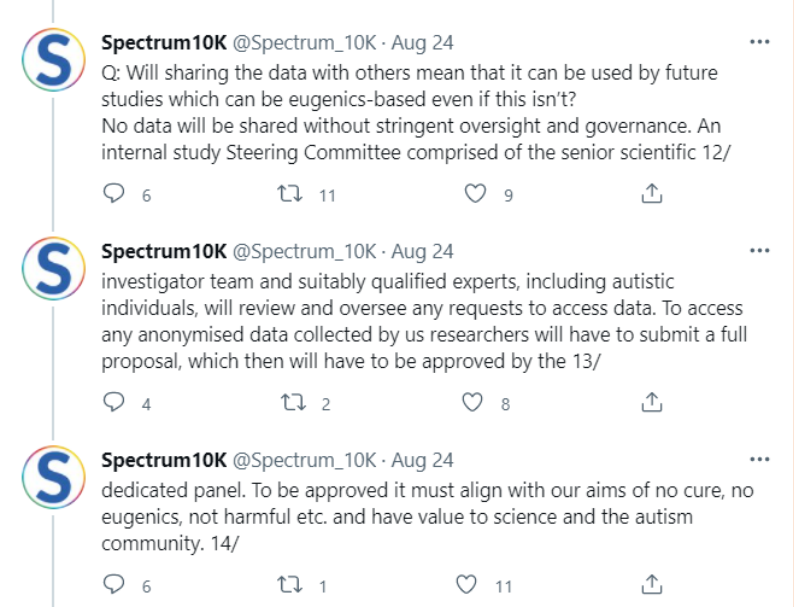
"Q: Are there autistic people involved in the process? How will you identify what is and is not eugenics. These teams have been known to lie in the past.

Autistic people will be part of our committee who makes the decisions about who to share data with, we are in the process 22/

of setting up this committee. Any data shared will be subject to a contract between research institutes which will explicitly state what it can and can't be used for. The wellbeing and support of autistic individuals and the autism community is our highest priority. 23/" END ALT TEXT

It is also specified that the steering committee will include the "senior scientific investigator team," (Reference https://twitter.com/Spectrum_10K/status/1430198220244783105?s=20 - SEE BELOW PICTURE WITH ALT TEXT), but the Participant Information Sheet

and the Consent Form do not explicitly or transparently state who these researchers are, their affiliations, or any/all of their conflicts of interest.



ALT TEXT: Screenshot of Spectrum10K @Spectrum_10K tweet: Aug 24, reads: "Q: Will sharing the data with others mean that it can be used by future studies which can be eugenics-based even if this isn't?

No data will be shared without stringent oversight and governance. An internal study Steering Committee comprised of the senior scientific 12/

investigator team and suitably qualified experts, including autistic individuals, will review and oversee any requests to access data. To access any anonymised data collected by us researchers will have to submit a full proposal, which then will have to be approved by the 13/

dedicated panel. To be approved it must align with our aims of no cure, no eugenics, not harmful etc. and have value to science and the autism community. 14/". ALT TEXT END.

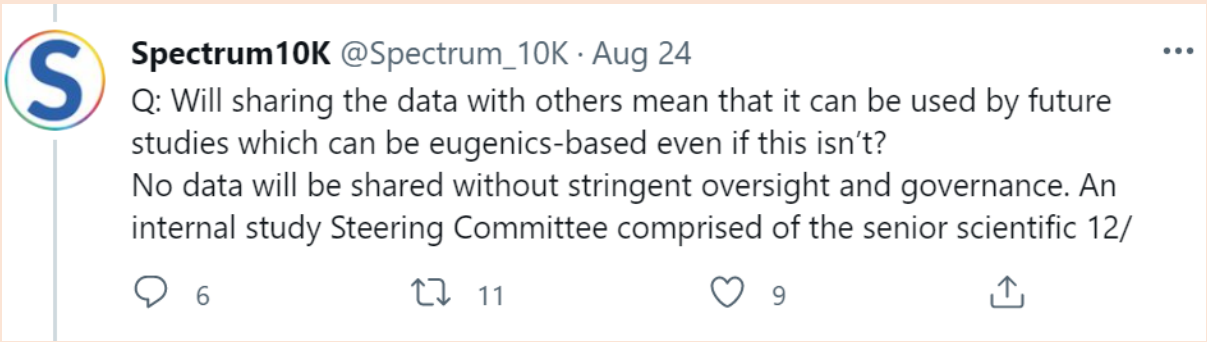
Therefore, potential participants do not have sufficient, explicit, or transparent information in order to be suitably informed about this study. It is not clear to any potential participant who is responsible for releasing the data from this study in the future, and prospective participants cannot possibly be made

sufficiently informed as the committee has not been set up ahead of participant sampling.

It is also not stated how many Autistic people would be on the Steering Committee, whether they would have majority say, or how many would represent the intersectionality of our Autistic community (e.g., Black people; people of colour; those with a learning disability; non-speaking Autistic people; gender and/or sexuality diverse people; etc.).

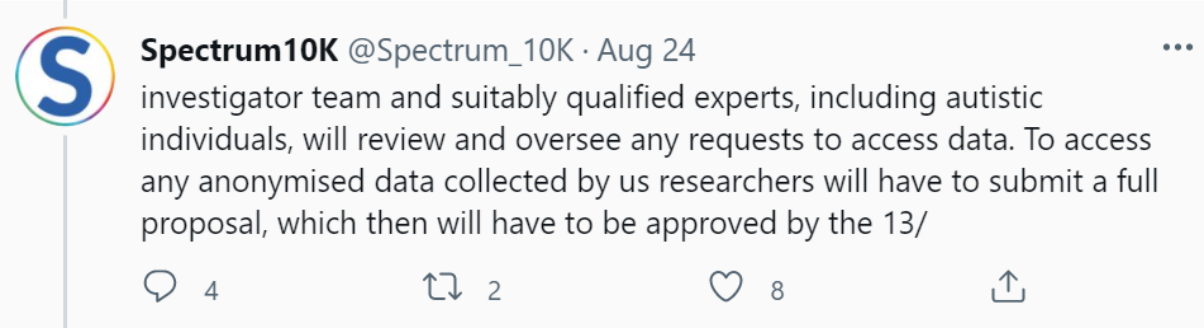
This study has been advertised to the public on the news, and Autistic ambassadors have been recruited to endorse this study, all prior to forming the Steering Committee. Further, the S10K social media account has told the public that a consortium has not yet been formed, when this is blatantly false (https://wellcome.org/grant-funding/people-and-projects/grants-awarded/common-variant-genetics-autism-and-autistic-traits).

PLAIN LANGUAGE SUMMARY: 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.



ALT TEXT: Screenshot of Spectrum10K @Spectrum_10K tweet: Aug 24, reads: "Q: Will sharing the data with others mean that it can be used by future studies which can be eugenics-based even if this isn't?

No data will be shared without stringent oversight and governance. An internal study Steering Committee comprised of the senior scientific 12/". ALT TEXT END



ALT TEXT: Screenshot of Spectrum10K @Spectrum_10K tweet: Aug 24, reads: "investigator team and suitably qualified experts, including autistic individuals, will review and oversee any requests to access data. To access any anonymised data collected by us researchers will have to submit a full proposal, which then will have to be approved by the 13/". ALT TEXT END

ALT TEXT: Screenshot of Spectrum10K @Spectrum_10K tweet: Aug 24, reads: "dedicated panel. To be approved it must align with our aims of no cure, no eugenics, not harmful etc. and have value to science and the autism community. 14/". ALT TEXT END

Further, it has not been made transparent, explicit, or clear what the definitions of "no cure, no eugenics, not harmful etc." are. Critically, it is not clear who the research study members believe has the authority to determine what is and is not harmful. Many Autistic people would argue it is Autistic people who should determine what constitutes harm.

This is why it is imperative that participants know who is represented on the Steering Committee before consenting. There is a history of research that has caused harm even when people believe that it has "value to [the] science and autism community" (Reference https://twitter.com/Spectrum_10K/status/1430198220244783105?s=20 – SEE ABOVE PICTURE WITH ALT TEXT). Autistic people deserve to know who is in control of their genetic data and what the Steering Committee would define as valuable, what they would define as eugenics, what they would define as not harmful, and what they would define as "no cure." For example, would a drug "treatment" for autism be considered a cure to this Steering Committee? Participants will have to make assumptions instead of being provided thorough, explicit, transparent, and clear information about what the criteria is for using this database.

PLAIN LANGUAGE SUMMARY: 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:

There are genuine and well publicised fears amongst the Autistic community around eugenics-based science and the potential development of 'screeners', such as those used to give pregnant parents the opportunity to abort children with Down Syndrome and other genetic differences.

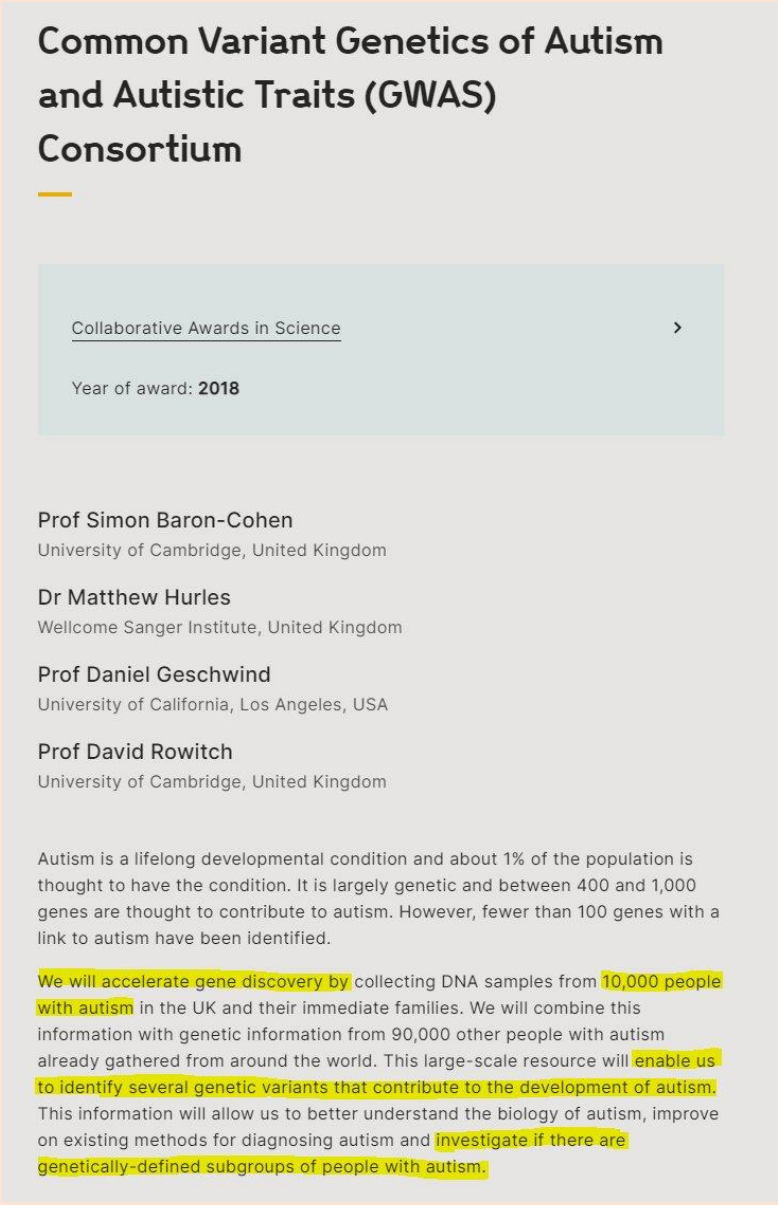
The fear is that genetic prenatal screenings would be used to identify Autistic babies in utero and give parents the opportunity to abort them.

The grant awarded to the researchers involved in S10K was for the collection of 10,000 DNA samples of Autistic people, stating the study will: 1) "identify several genetic variants that contribute to the development of autism"; 2)

"investigate if there are any genetically-defined subgroups of people with autism"; and 3) "Improve on existing methods for diagnosing autism" (link - "Wellcome grants awarded 1 October 2005 to 30 June 2021 as at 12072021" - https://wellcome.org/reports/grant-funding-data-2019-2020#downloads-3747).

The S10K study has not explained these aims to the public, and this GWAS grant award does not mention anything regarding improving Autistic people's wellbeing or focusing specifically on co-occurring conditions rather than only autism. However, S10K is publicising that these are the purpose of the study. The actual description of the grant application that was awarded states "The proposed research aims to accelerate the discovery of common, low frequency, and copy number variants in autism and autistic traits" without any mention of improving Autistic people's well-being or researching co-occurring conditions. This lack of transparency regarding what this data will be used for in the future, and the lack of transparency of what has been stated it will be used for based on the awarded grant summary description, is clearly unethical.

It is important to note that the original summary for the Common Variant Genetics of Autism and Autistic Traits (GWAS) Consortium grant awarded for this project (https://wellcome.org/grant-funding/people-and-projects/grants-awarded/common-variant-genetics-autism-and-Autistic-traits – SEE BELOW PICTURE WITH ALT TEXT) is solely focused on identifying "several genetic variants that contribute to the development of autism", and does not mention "co-occurring conditions", as S10K have stated on Twitter. Further, they have plans to combine the 10,000 genetic dataset they collect with 90,000 other Autistic people's DNA to specifically "identify several genetic variants that contribute to the development of autism". It also states that this study will "investigate if there are genetically-defined subgroups of people with autism" without mentioning anything about co-occurring conditions. If these researchers already have funding to do this, and this is planned, participants have a right to know about it. However, none of this information is anywhere on their website, the Participation Information Sheet, or the consent forms.



Common Variant Genetics of Autism and Autistic Traits (GWAS) Consortium

Collaborative Awards in Science

Year of award: **2018**

Prof Simon Baron-Cohen
University of Cambridge, United Kingdom

Dr Matthew Hurles
Wellcome Sanger Institute, United Kingdom

Prof Daniel Geschwind
University of California, Los Angeles, USA

Prof David Rowitch
University of Cambridge, United Kingdom

Autism is a lifelong developmental condition and about 1% of the population is thought to have the condition. It is largely genetic and between 400 and 1,000 genes are thought to contribute to autism. However, fewer than 100 genes with a link to autism have been identified.

We will accelerate gene discovery by collecting DNA samples from 10,000 people with autism in the UK and their immediate families. We will combine this information with genetic information from 90,000 other people with autism already gathered from around the world. This large-scale resource will enable us to identify several genetic variants that contribute to the development of autism. This information will allow us to better understand the biology of autism, improve on existing methods for diagnosing autism and investigate if there are genetically-defined subgroups of people with autism.

ALT TEXT: Screenshot of Wellcome.org funding award, reads:

"Common Variant Genetics of Autism and Autistic Traits (GWAS) Consortium

Collaborative Awards in Science; Year of award: 2018; Grantholders: Prof Simon Baron-Cohen, University of Cambridge, United Kingdom; Dr Matthew Hurles, Wellcome Sanger Institute, United Kingdom; Prof Daniel Geschwind, University of California, Los Angeles, USA; Prof David Rowitch, University of Cambridge, United Kingdom.

Project summary

Autism is a lifelong developmental condition and about 1% of the population is thought to have the condition. It is largely genetic and between 400 and 1,000 genes are thought to contribute to autism. However, fewer than 100 genes with a link to autism have been identified.

We will accelerate gene discovery by collecting DNA samples from 10,000 people with autism in the UK and their immediate families. We will combine this information with genetic information from 90,000 other people with autism already gathered from around the world. This large-scale resource will enable us to identify several genetic variants that contribute to the development of autism. This information will allow us to better understand the biology of autism, improve on existing methods for diagnosing autism and investigate if there are genetically-defined subgroups of people with autism." ALT TEXT ENDS.

Another fear is that early or in-utero screenings would encourage identification of an Autistic person and then psychological interventions from an early age to normalise an Autistic child through the use of behavioural therapies and social skills training, known to correlate with post-traumatic stress responses and symptoms (Kupferstein, 2018).

The project only attempts to alleviate those fears by stating that in itself the project does not agree with eugenics, and that data will only be passed onto projects that meet the same standards of ethics S10K apply to themselves, which as stated are vague, opaque, and obfuscated (obscure).

PLAIN LANGUAGE SUMMARY: Autistic people are worried that even though S10K 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.

DEHUMANISING NARRATIVES, RHETORIC, AND RESEARCHERS' CONFLICTS OF INTEREST:

Dehumanising rhetoric (https://theAutisticadvocate.com/2020/02/regarding-the-use-of-dehumanising-rhetoric/): the way in which autism and Autistic people are spoken about by the S10K project and its key researchers is a clear indication of the attitudes driving this projects aims as stated in the funding awarding body (https://wellcome.org/grant-funding/people-and-projects/grants-awarded/common-variant-genetics-autism-and-Autistic-traits)

It is impossible to trust the S10K project when its key researchers hold public attitudes like the following:

"Autistics lack the quintessential part that makes us human" (Simon Baron-Cohen referring to his misperception that Autistic people lack empathy; https://docs.autismresearchcentre.com/papers/2001_BC_review.pdf)

"If you're interested, even in a more abstract way, in human behavior and human cognition, autism is an extraordinary window into that. [Autism] involves dysfunction in social cognition, language — the things that are really part of

what makes us human" (Daniel Geschwind https://www.spectrumnews.org/news/profiles/daniel-geschwind-after-many-detours-on-the-trail-of-autisms-genetics/).

The men leading the Spectrum 10K project have defined Autistic people as inhuman or not human. Yet these are the people responsible for policing the ethical standards of this study, and they do not view us as human.

PLAIN LANGUAGE SUMMARY: 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.

THERE ARE FURTHER CONCERNS ABOUT THOSE LEADING THE PROJECT:

Simon Baron-Cohen is known for having created (now debunked) theories that have caused the most harm to Autistic people, particularly women, people of marginalised genders, and some boys and men who do not meet the narrow stereotype Baron-Cohen endorses and perpetuates. Simon Baron-Cohen's debunked "theory of mind", "extreme male brain", and "systemising-empathising" theories of autism are responsible for the inaccurate and damaging stereotypes that exist about Autistic people and our experiences. He has fed the rhetoric that we have no empathy, that only, or largely only, boys/men/males are Autistic. This has led to whole lost generations of Autistic people. There are thousands if not hundreds of thousands of Autistic people whose mental health have been damaged by not knowing they are Autistic or discovering this later in life because they do not fit his narrow view of "subgroups" he hopes to maintain (still propagated by him through book sales; Gernsbacher, 2019).

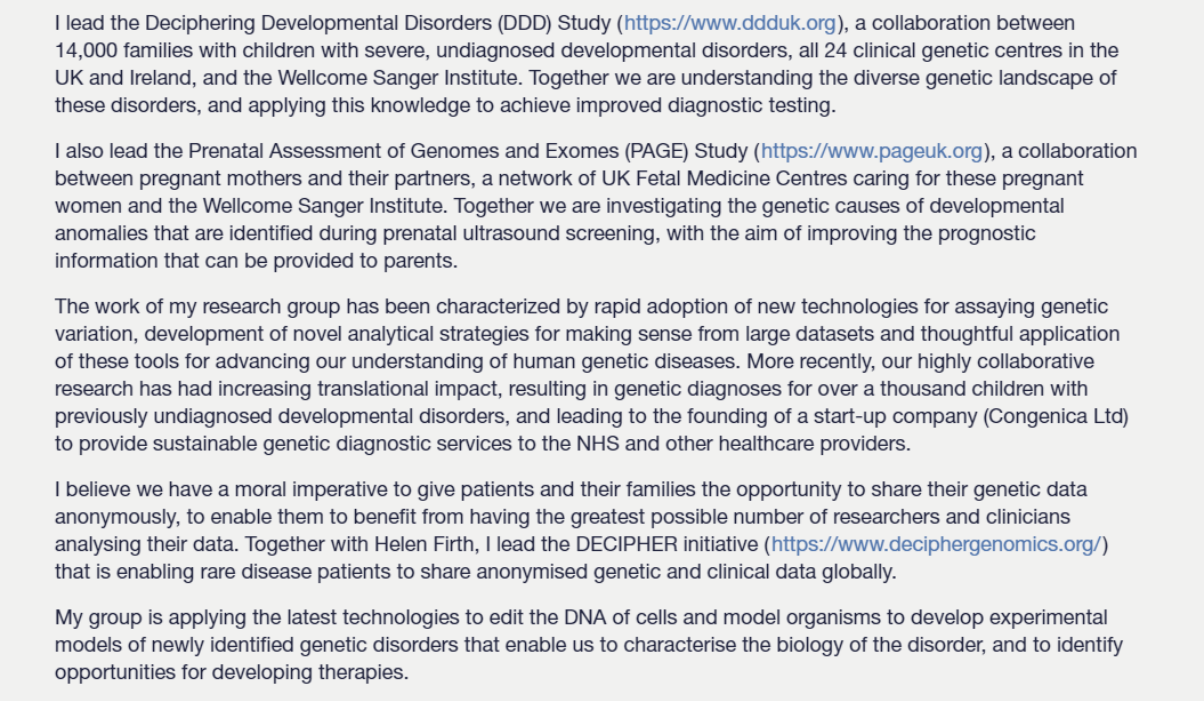
Daniel Geschwind leads an organisation called the Centre for Autism research and Treatment, he personally has a history of animal testing (particularly focusing on 'Autistic mice' research, often derided amongst the Autistic community), stem cell research looking for causes and interventions for Autism; and CART that invoke the use of Applied Behavioural Analysis for behaviour

modification (a method known to increase the likelihood of PTSD; Kupferstein, 2018).

Both men have strong links to organisations abhorred by many members of the Autistic community, such as Autism Speaks and AIMS-2 Europe. Geschwind was the first chair of an organisation called Cure Autism Now, which later merged with Autism Speaks with whom he has a very long and close association.

There is so much historic mistrust of Simon Baron-Cohen within the Autistic advocacy and academic communities for many valid reasons; and now the same with Daniel Geschwind. There is also mistrust and opposition to many of the organisations both men are associated with currently - as such we are confused as to why there was no thought to alleviate concerns prior to this.

Matthew Hurles, who is a researcher on the GWAS grant, leads the Prenatal Assessment of Genomes and Exomes (PAGE) Study, which investigates "the genetic causes of developmental anomalies that are identified during prenatal ultrasound screening" (link - https://www.sanger.ac.uk/person/hurles-matthew/). Further, Matthew Hurles has a start-up company called Congenica Ltd seeking "to provide sustainable genetic diagnostic services to the NHS and other healthcare providers." This is clearly a conflict of interest but has not been told to participants regarding future research that may occur. Participants have a right to know which researchers may gain access to their dataset and what other research interests they may have surrounding autism with real potential concerns for prenatal screening tests to be implemented from the analysis of this data.



I lead the Deciphering Developmental Disorders (DDD) Study (https://www.ddduk.org), a collaboration between 14,000 families with children with severe, undiagnosed developmental disorders, all 24 clinical genetic centres in the UK and Ireland, and the Wellcome Sanger Institute. Together we are understanding the diverse genetic landscape of these disorders, and applying this knowledge to achieve improved diagnostic testing.

I also lead the Prenatal Assessment of Genomes and Exomes (PAGE) Study (https://www.pageuk.org), a collaboration between pregnant mothers and their partners, a network of UK Fetal Medicine Centres caring for these pregnant women and the Wellcome Sanger Institute. Together we are investigating the genetic causes of developmental anomalies that are identified during prenatal ultrasound screening, with the aim of improving the prognostic information that can be provided to parents.

The work of my research group has been characterized by rapid adoption of new technologies for assaying genetic variation, development of novel analytical strategies for making sense from large datasets and thoughtful application of these tools for advancing our understanding of human genetic diseases. More recently, our highly collaborative research has had increasing translational impact, resulting in genetic diagnoses for over a thousand children with previously undiagnosed developmental disorders, and leading to the founding of a start-up company (Congenica Ltd) to provide sustainable genetic diagnostic services to the NHS and other healthcare providers.

I believe we have a moral imperative to give patients and their families the opportunity to share their genetic data anonymously, to enable them to benefit from having the greatest possible number of researchers and clinicians analysing their data. Together with Helen Firth, I lead the DECIPHER initiative (https://www.deciphergenomics.org/) that is enabling rare disease patients to share anonymised genetic and clinical data globally.

My group is applying the latest technologies to edit the DNA of cells and model organisms to develop experimental models of newly identified genetic disorders that enable us to characterise the biology of the disorder, and to identify opportunities for developing therapies.

ALT TEXT: Screenshot of Mathew Hurles biography.

In a recent overview of the history of theorising about autism, Vivanti and Messinger (2021, p. 8) offer a concluding statement that highlights our concerns outlined above:

"Theories—whether explicit or implicit—shape the questions that researchers ask, the methods they use to test them, and the way the resulting data are interpreted. They also guide the work of practitioners and policy-makers, and influence societal attitudes and opinions… [R]esearch efforts need to extend beyond the biological and behavioral features of autism, and examine the explicit and implicit theories that guide individuals, systems and institutions interfacing with autism, in the effort to creating a more autism-friendly society".

The S10K is ignoring the advances in discussion around humanising Autistic people and asking us what we want when it comes to research about us.

PLAIN LANGUAGE SUMMARY: 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.

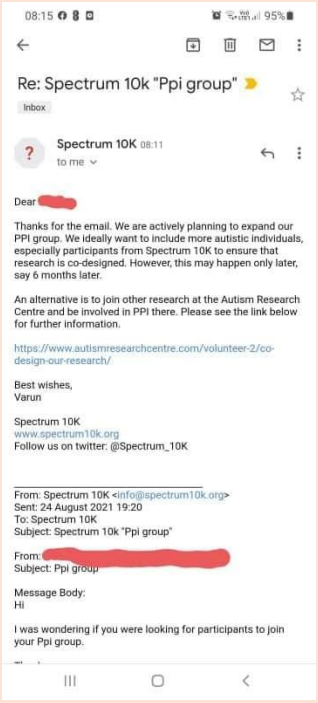
CO-PRODUCTION:

Academia is starting to accept that the most valid form of research not only incorporates Autistic voices, but engages in co-production, where ideas are formulated by advocates and academics together, then applied by advocates and academics. Simon Baron-Cohen sits on the editorial boards for the academic journals 'Autism' and 'Autism in Adulthood', an immensely important practice in academic publishing that comes with an enormous amount of responsibility and knowledge of the narratives around autism. Indeed 'Autism' has just published a whole new set of publishing guidelines directed at both uplifting Autistic voices and prioritising the Autistic community's priorities for research, and the latter has publishing guides around co-production based on the work of AAspire (Academic Autism Spectrum Partnership in Research and Education).

There is no evidence of co-production in any of the S10K project and, despite repeated questioning, there has been no confirmation that openly Autistic, or any Autistic researchers have been involved in the creation or design of the study; only that an advisory panel that met 1-2 times a year, and included only 4 Autistic people out of 11 people (5 non-autistic parents and 2 non-autistic clinicians), and they have not given information about whether these Autistic people are researchers. Given they are hoping to collect DNA data from 10,000 Autistic people, there is no excuse for not including Autistic people at every level of the project.

A recent (since the announcement of the study) request by a member of the Autistic community to join the S10K Patient and Public Involvement group (PPI - a group that represents stakeholders affected by the research) was turned down with this statement:

"We are actively planning to expand our control group. We ideally want to include more Autistic participants from Spectrum 10k to ensure that the research is co-designed. However, this may happen later, say 6 months later."



ALT TEXT: Screenshot of anonymised email response from S10K when asked to join the S10K Patient and Public Involvement group. Reads:

"We are actively planning to expand our control group. We ideally want to include more Autistic participants from Spectrum 10k to ensure that the research is co-designed. However, this may happen later, say 6 months later."

Participants in a study should not also be participants in the PPI group. Clearly Autistic people have not been involved in the formulation and application for the grant for this project. If people are being asked to co-design the research in 6 months' time, this calls into question what S10K has received funding for.

There is phenomenal mistrust among many Autistic people of autism research. The aims and priorities of much research is focused on biology and behavioural interventions with very little focused on quality-of-life outcomes from an Autistic perspective.

The S10K research project does not meet the basic recommended inclusive guidelines or standards of either of the two journals the lead researcher Baron-Cohen sits on the editorial boards of.

PLAIN LANGUAGE SUMMARY: 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:

There has been much talk by the S10k project regarding quality of life for Autistic people. The project claims to want to improve the mental health and wellbeing of Autistic people, but at no point does it substantiate what this means.

There is little evidence to show that the S10k project understands what good quality of life for Autistic people looks like, or how the study would achieve this.

There is no explanation or transparency as to what constitutes Autistic quality of life or who is making the decisions as to what constitutes Autistic quality of life for this project. Given there are no Autistic people substantially involved in the study set up so far, any consideration as to what constitutes Autistic quality of life will have been made by non-autistic researchers.

We already have substantial evidence as to why Autistic people have poor mental health. For example, we are more likely to be victims of abuse – a study that Baron-Cohen himself co-authored (Griffiths, et al., 2019).

To quote Baron-Cohen (BBC Breakfast, Tuesday 24th of August 2021):

"They [participants] just spit in a tube, send it back to us so we can look for the genetic causes of autism."

It is entirely disingenuous for Baron-Cohen to claim that we do not know why some Autistic people have poor mental health, and for the study to state a wholly tenuous link between collecting Autistic people's DNA in order to determine genetic foundations of autism and Autistic wellbeing/quality of life.

Further, Baron-Cohen mentioned nothing about looking for the genetic causes of poor mental health (a vague term); depression; or sleep difficulties to solve quality of life problems.

The public project materials claim that sleep quality, anxiety and depression are all rooted in genetic factors. These claims are largely erroneous and have no strong empirical evidence to support them. We would be extremely interested to see the evidence that supports the claims with which this project is founding many of its premises on.

The S10K project is clearly operating from a pathology paradigm (Walker, 2016) perspective. This is in direct conflict with the perspective of the actually Autistic community who overwhelmingly prescribe to the neurodiversity paradigm and the social model of disability (Gray-Hammond, 2021).

PLAIN LANGUAGE SUMMARY: 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:

Much focus in academic research in the last few years has turned to marginalisation, stigma, and the role of society in the poor mental health and well-being outcomes of Autistic people, but S10K seems to have conveniently ignored this to justify DNA collection solely from Autistic people.

If co-occurring conditions (S10K highlights epilepsy for example) are at the heart of the biological purpose of the S10K study and genetic in nature, and DNA samples are being collected on that basis, why is the study not based on the outlined co-occurring conditions and include non-autistic participants who also have issues with those factors. If the claim is about well-being and that some well-being factors are co-occurring conditions, then why are only Autistic people being targeted?

Not only is this perplexing and confusing and another glaring concern, we firmly believe it highlights a disconnect between this project and the community it allegedly seeks to serve. It also points overwhelmingly to dishonest intentions, particularly as the funding summary focussed solely on "identif[ying] several genetic variants that contribute to the development of autism…to better understand the biology of autism, improve on existing methods for diagnosing autism and investigate if there are genetically-defined subgroups of people with autism".

PLAIN LANGUAGE SUMMARY: 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:

One of the claims made by the project is that it is necessary to identify subtypes in Autistic presentation in order to identify if people are more

susceptible to various co-occurring conditions. This is something we greatly refute.

The debate around subtypes in Autistic presentation has existed since early categorisation of Autistic experience. Subtypes were removed from the diagnostic criteria for both empirical and political reasons.

The recent diagnostic manuals (DSM5 and ICD11) updated their definitions for autism spectrum disorder to remove the issues found in early definitions that sought to subtype, subgroup, and/or subcategorise Autistic people. This was done based on years of evidence that Autistic people move in and out of subcategories, rendering them invalid and impractical (Wodka, Mathy, & Kalb, 2013). This included the decision to remove Asperger's as a separate diagnosis.

Subgrouping could potentially be used to separate Autistic people into groups which are deemed "low-functioning" ("from learning disabilities"), or valueless to society, or "high-functioning" ("through to talent"; BBC Breakfast with Simon Baron-Cohen, Tues 24th Aug, 2021; & https://adminoxy.com/project-coordinator-fixed-term,i5868.html) and therefore have value to society. Given the consideration and evidence used to come to the decision to remove subtyping from diagnostic manuals (a decision that included Autistic people's input), and allow for a more nuanced diagnosis, subtyping would for many Autistic people and their families be a very unwelcome step backwards.

PLAIN LANGUAGE SUMMARY: 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:

At launch, S10k made good use of celebrity endorsers via social media and television and radio marketing.

We feel this is a very transparent marketing attempt to assuage people's concerns, pacify advocates and paint a picture of trustworthiness. The celebrity ambassadors do not convey any in-depth knowledge of the project, they appear to be reading from scripts and when publicly pressed about concerns, one responded:

"I asked lots of questions, why don't you do that too?"

The use of celebrity endorsement creates an impression that the S10k project assumes that Autistic people, parents, and carers are not capable of doing their own research or making their own decisions, and that providing 'safe' faces and voices will mitigate worries and questions. This is not only extremely patronising and ableist, but a perfect example of the extreme privilege in academia.

Autistic people, parents, and carers are not able to make an informed decision all the while the information is gatekept, and the documents available are purposefully convoluted, confusing, and misleading, obfuscating (obscuring) the project's aims and objectives.

We also have great concern over the actions of these 'Ambassadors' and the way they have acted on social media.

One of the Autistic ambassadors has an open record of racism, transphobia, and far right commentary on their social media and reacted aggressively to those who challenged the validity of this research.

A celebrity Ambassador has made the assertion that those who oppose this research are in some way anti-science, or fearful of science and conspiracy theorists - even when many of those opposing this research are scientists and advocates who work alongside and within academia. He has also given out information that directly contradicts that given out by the project.

Others have been dismissive of concerns and when pushed have deleted social media posts rather than answer questions.

The way the ambassadors have responded to genuine and factually based criticism of this project is, to us, indicative of the intent of the project. There are very real concerns and fears out there, and for those to be dismissed and told that critiquing this project is anti-science is another level of the marginalisation, invalidation, and dehumanisation faced by Autistic people on a daily basis and is being recognised now by research.

It also feels complicit: that there is something to hide. It is very easy to make the logical leap that the thing hiding is the endgame of the project: that it will act as a gateway to the fears mentioned earlier around eugenics, screening tools, and interventions. Not to mention the concern over who will own whole copies of individual people's genomes in the future, because of this project.

Another concern about the ambassadors is the inclusion of Autistica and its listing as an advocacy organisation. Autistica are a controversial organisation for the Autistic community, for similar reasons to those stated in this document and further, more complex ones less relevant to this statement.

Further to the lack of Autistic involvement in the process of creating this research: on the BBC television launch of this project not a single Autistic person was included.

When a known and respected Autistic community advocate was invited to an early BBC4 radio interview about the project, armed with her logical questions, she was railroaded by the presence of Baron-Cohen himself and given no opportunity to put her questions to him. As an Autistic person she was deeply distressed that she had not been informed that Baron-Cohen himself would be there and was not given the chance to ask her questions – changes like this are cruel to an Autistic person who was given expectations of how the interview was to proceed.

Again, we suggest this provides further evidence of the extreme disconnect between the project leaders and the community they seek to research.

PLAIN LANGUAGE SUMMARY: 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:

Much around this project, including the aims and objectives and answers when questioned, are vague and contradictory. As a collective we are astounded this project received funding and ethical approval.

We have concluded that the materials approved for public dissemination are inconsistent, ambiguous, non-specific, and quite simply, have too many aims to be a viable study.

The materials make too many nebulous claims about what the study will achieve; achievements that genetic studies dedicated to individual experiences such as Ehlers Danlos Syndromes; ADHD; depression etc. have not been able to accomplish in (sometimes) decades.

We assume the aims and objectives must have been made very clear to funding bodies, but the fact that they have not been made explicitly clear to the public is hugely concerning. The confusing and often chaotic nature of explanations and responses leaves us as a collective gravely concerned at the methodology and veracity of this research, especially when there is historical precedent for prenatal screening tests for disabilities that are not life-threatening, such as Down Syndrome.

As one academic put it:

"My sense is that genetics research projects like Spectrum 10k are requiring Autistic people to have a level of trust in autism research that most autism researchers absolutely have not earned."

Our concerns around this, as both Autistic and non-autistic advocates, academics, and professionals are enormous and as a result we cannot support or condone this research in any way; and indeed, we will actively warn Autistic people, parents, and carers away from taking part.

We also question the funders and ask why such a clearly overly optimistic, woolly, and unclear project has been funded, and how it has passed any ethics boards.

In short, it is, at best, a study lacking not only Autistic co-production, but also lacking a thorough understanding of Autistic experience and wellbeing. At worst, this is a thinly veiled attempt to DNA data mine at the expense of the Autistic community.

PLAIN LANGUAGE SUMMARY: 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:

Due to the above, we insist on the full publication of the full application as it was approved for funding, in order for full transparency of this study to be reached.

We also insist on the re-evaluation of the study by the ethics awarding body.

PLAIN LANGUAGE SUMMARY: 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.

END

As well as signing this statement below - which will be sent to Health Research Authority and the bodies that awarded S10K funding – please consider signing the following petition https://www.change.org/p/university-of-cambridge-stop-spectrum-10k?utm_content=cl_sharecopy_30481620_en-GB%3A4&recruited_by_id=264d2700-09af-11ec-8010-8d53b4d8f0ca&utm_source=share_petition&utm_medium=copylink&utm_campaign=psf_combo_share_initial

Signed: