

# Transcript of the Webinar 1 questions and answers

## Topic: aims of the study

Date of webinar: Wednesday 10<sup>th</sup> May

### Introduction

Audio recordings were made of each of the webinars and transcripts were made of these. The following questions and answers are what was recorded in webinar 1 and are set out below. The only edits that have been made are to remove filler words (for example 'um') and repeat words. Some footnotes have been added which provide post webinar clarifications from the Spectrum 10K team.

**Question:** The Spectrum 10K Study Team have said publicly that they won't be looking into the causes of autism, yet correspondence between Spectrum 10k and NHS trusts has revealed members of the research team confirmed that to study teams that they are looking for the causes of autism. So why is there this discrepancy?

**Answer:** The key word in this question is about causes. The causes of autism. It ties in nicely with what this webinar is all about, which is what are the aims and objectives of the study? Causes is actually a very tricky word: to ever prove that something causes something else. I'm going to start off by saying that the aim, the aims of the study, are to look for the genetic and environmental factors that contribute to autism, and the genetic and environmental factors that contribute to the co-occurring conditions. But actually, I think this question has, they've put their finger on a much more complicated word, how do we ever know that something causes something? It's a really tricky one, in terms of if there's any nervousness about if scientists look for contributing factors, is this part of trying to prevent autism? The answer is clearly 'no' on our part. Our research is not designed or have any agenda to prevent autism. Even if we find contributing factors, it's really just to understand autism and understand the links to the co-occurring conditions. But other members of the panel may want to elaborate.

The second part of the question was about is there a discrepancy between what was revealed by (participant), and what we've said. I think on our part, we don't perceive any discrepancy. I've tried to state it really clearly, that the study is aiming to find factors that contribute to autism and contribute to co-occurring conditions.

**Question:** What can you tell us about the organisation funding this project? Do they have an opinion on this consultation, and the resulting delays to the project?

**Answer:** We have spoken to the funder, which is the Wellcome Trust, they've really welcomed us pausing the study, they actually think this is kind of setting a really good example to the research community, that anytime you're doing human research with any group of people, if there are concerns by the group of people that you are studying, stop and listen, talk, find out what their concerns are, and see if the study can be improved. This is kind of a new way of doing research, and the funder, the Wellcome Trust, which is the biggest biomedical charity that funds research in that area, they're looking at this with support. They're really interested to see how the study changes as a result of dialogue. So they're not worried about the delays; they would much prefer that we get the study right.

They've also encouraged us to feed back any learning that we that we get from the consultation. They are very interested to see what we learn, and how those learnings can be implemented going forward for other projects. So overall, I think they're very supportive.

**Question:** What's the point of making a study, if you won't be able to share your findings? Perhaps you could make some comments about the study findings and how they'll be shared.

**Answer:** My short answer is that, of course, we'll be sharing the findings. All scientists, we're no exception, have got a responsibility to share the results of their study. And they do that through journal articles. So that's publications which go through the peer review process, and at scientific conferences. And then outside of academia. Many of us also engage in communication in all kinds of forums, whether it's festivals for the public to find out more about science, magazine articles, so all kinds of different ways of sharing findings.

But maybe this question was also about sharing data. And that's going to be the subject of a separate webinar. But the brief answer to the sharing data bit, is any data that people provide, as a participant stays within our team in Cambridge. So only our team will look at it. So we share it within each other<sup>1</sup>. You're actually looking at the team here. It's quite a small team. There's more of us who are not here today, but it's a very small team, and anyone outside of our team who wants to share the data, the suggestion that we've got on the table, but this is for the consultation, is it should go through a Data Access Committee, which will be, I think, comprised of all the key stakeholders, obviously autistic people, and their parents or families or carers, and scientists, and maybe clinicians, all of this has to be decided. But data sharing with people outside of the people you can see on this screen, our little team will have every opportunity to be vetted by a Data Access Committee.

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<sup>1</sup> The Spectrum 10K team would like to clarify that when a participant takes part in Spectrum 10K, access to data stays within the Spectrum 10K team. However, any applications to Spectrum 10K data by academic researchers within the Autism Research Centre or other external academic researchers will be vetted by a Data Access Committee which will include autistic participants.

We have an opportunity in front of us to decide the shape of the Data Access Committee and what sort of research requests we must encourage so that we can share the data. And none of these things are decided yet. And we're still hoping through this, and the co-creation process that happens after this, we can decide some of those things.

We have an amazing opportunity here to be completely transparent about what data gets collected, and that's all part of this consultation and co-creation process. And then who outside of the Cambridge team ever gets access to it? I think this is groundbreaking in putting the power into the hands of autistic people and their families just as much as into the hands of scientists. This really will be a model of partnership, in what happens to data of this kind.

**Question:** You've sent out the phase one, phase two, in a very user friendly way to say, would there be an area whereby the preliminary findings would be actually available to the cohort? E.g. more than just this is what we've said this is what we've found etc..

**Answer:** We will be making summaries available, not just for scientists, where often that's full of jargon, but for non-scientists too. And without simplifying their findings, because non-scientists are the same, they have the same capabilities of understanding what the study is showing, but we'll just be making sure that they're in what you call the user-friendly format.

We're here because we want to be totally transparent and invite conversation and dialogue. And people will have heard in the news that there is what [participant] called a challenge of how to make sure that we're working openly together, that's to say, scientists and the autism community and Leneh is a good example of someone who wears both hats. But we, by making available summaries in technical and non-technical format, we hope that we can achieve that transparency and therefore have that very strong trust between the different stakeholders.

**Additional answer from the consultation co-lead:** The plan for what to do with the findings from the consultation, we have to work super fast. So, we're actually going to start working even before we've written the report. We're gonna look at everything that everybody said, in the survey and in the webinars, and we're gonna look at them one topic at a time, so that we can start to work with the co-production group immediately when the consultation closes. You might have to wait a little while to get the full report, because writing those sorts of things takes a long time, especially when I'm involved because I'm not the quickest. It will be out there and it will be published, but it might take longer than actually making the changes will.

**Question:** Autism is referred to as the spectrum. How is it possible to apply a one size fits all solution to the causes of autism? I have Asperger's and my perception of the world I live in varies enormously from a friend of mine, who also has Asperger's.

**Answer:** This is actually going to the heart of some of the science in the project. My quick answer is that there are so many different dimensions of difference within the autism community, we could just give some examples; language is one good example of a dimension of difference where some people manage with spoken language, and others prefer written language, or sign language, or using tablets, or all kinds of different methods of communication, that will just be one dimension. But we could think of others like the sensory dimension, or the anxiety dimension, or social motivation. There's so many different dimensions. What the scientists are going to be doing when all the data comes in, is using statistical methods to try and identify... We don't think there's a one size fits all solution; we think there are multiple dimensions that we need to try and understand. You are absolutely right, that even two individuals who both have a diagnosis of Asperger's may be totally different to each other. And that's part of what this study will allow us to investigate. And I'm going to invite a Spectrum 10K team member to say it better than I have.

**Additional answer from Spectrum 10K:** There are differences within autism, that there's also a strong underlying similarity. And we see that at the level at multiple levels, genetics, so on and so forth. When you look at the genetics of autism, you see that there are shared underlying genetics that similar across most of the people but on top of that are also individual aspects, both individual social environments, individual, other environments, individual genetic variants, which contribute to those dimensions. And you're absolutely right, that there is no one size fits all. I don't think that is unique to autism. I think that's also seen across multiple different neurodevelopmental conditions we've seen across mental health conditions. It's also seen in physical health conditions, for example. And that's precisely what we're trying to see what are the different factors that are shared and different so that we can provide perhaps better, more precise support or takeaways by which we can provide more precise support to autistic people who do need them.

**Question:** What is the possible path from genetic research to actually helping autistic people?

**Answer:** There are some potential paths, and I'm saying potential because possibilities is still quite a strong word. So some examples where we know for example, in some groups of autistic individuals, people have identified, and this is very, very rare in number of individuals, that people have identify certain genetic variants, which have not just an impact on autism, but also profound co-occurring conditions. One particular example that I always quote, very rare variations in this particular gene called CHD-8, which often but not always causes autism, but almost always causes severe gut issues. We know that several autistic people have different types of gut issues, and they are caused by different mechanisms, but in this particular example, scientists have identified what exactly the mechanism is, and the mechanism is that the nerves that surround the intestine are not working properly. As such, there are motility issues in the intestine. So the food is not passing through quite easily. And I believe they are

ongoing ways to try and - because they are non-standard lining the alimentary canal, you can target them specifically. And people are trying to develop mechanisms by which they can try and target that, to help with the issues among these few individuals. These are extremely rare. So we're talking about 10s of individuals, 10-20 individuals across the world. But that's just one general possibility as to if we find some of these ways, perhaps we need, we may have medical support.

These kinds of pathways to helping autistic people are outside the timeframe of this study. What this study will allow us to do is collect all the relevant data. We've said that the data is genetic, and environmental, and what scientists called phenotypic, which is descriptions about you, and how your mind and behaviour how you think and how you act. But translating it, finding that path to using this data to help people is outside of the timeframe. We've probably only got about two years, realistically, to collect all this data. I think a Spectrum 10K team member gave a nice illustration, that even from one gene, that might open up a window into helping people who've got gastrointestinal pain, but they could have given other examples to do with epilepsy, or anxiety. And anxiety is maybe a good example where we wouldn't be looking particularly in the genome, we'd be looking at experience, experience of stigma, experience of lacking educational support in primary school or secondary school. All of all of these factors will be collected through questionnaires as part of the study.

**Question:** So are you actually doing anything with what you're collecting? Are you only collecting it for future years?

**Answer:** So we're collecting the data. And then we're going to analyse as much as we can, within our small team. But the analysis is really showing what is associated with what. That's probably the limit of what we can do within this study. It's sometimes called an association study. What is associated with what. Are these five factors associated with this kind of outcome. That's probably the limit to what we can do within this study. But you can imagine beyond this study, once that knowledge is available, other teams will pick up the finding, and turn it into what you called a pathway to support. And it might be a new medical approach for medical symptoms causing distress. It might be a new educational approach for kids who need to learn in a different way to avoid an unwanted outcome, like depression or suicidality. These things are like outside of the study, but the study will collect and analyse as far as it can these associations.

**Question:** How was the consultation funded? The consultation, not the study.

**Answer:** As you are all aware, this consultation is a large piece of work. And it's been very important to us as a team and more broadly within the Autism Research Centre that we do it properly. So we were very fortunate to find Hopkins van Mil and are very privileged to get to

work with them and with Leneh in this manner, to support that. This work was not funded within the original grant, so we did have to identify an additional source of funding and we were able to apply for a grant through the Wellcome Trust for a research engagement grant, which allowed us to not only support this consultation, but also look at how we could develop and evolve our engagement practice throughout the ARC. So that looked at not only just this engagement, but also developing a communications team, making sure that we work with the autism community from the study design phase, and build in our learnings from this experience going forward. So to answer your question that the consultation has been funded by the Wellcome Trust also through a separate grant.

A second grant was within the University of Cambridge. So as well as the Wellcome Trust, being very supportive of this consultation, and actually funding these webinars and all the work that goes around it, the survey, and so forth. So is the University of Cambridge, so internal money from the university they want to see science being done. But they also want to see it being done responsibly. And with the full input of the people who may be beneficiaries, or feel the impact of research. So they've given money towards this as well.

And then the other thing I wanted to pick up on is that Spectrum 10K is only one of about 30 projects that the Autism Research Centre is conducting. But the learnings already from this study have carried over to all of our other studies.

[At this point in the webinar the following link was shared in the Chat:

<https://www.autismresearchcentre.com/community-engagement-commitment/>]

We've released on our Autism Research Centre website. It's a commitment from all of our scientists to conduct community engagement with every project, not just ones that involve genetics, which we understand have a particular sensitivity, but all of our studies, which include studies into, for example, why autistic people are more at risk of being arrested and ending up in the criminal justice system, why autistic people are more likely to end up homeless or unemployed, or in other examples of vulnerability. Every one of our projects we're looking at how autistic people experience pregnancy, a wide range of of research projects. But we want to make sure that autistic voices and the voices of carers of autistic people are always involved in every project.

**Question:** How do we ensure that any further studies use the results of this study for the benefit and not to the detriment of the autistic community? As a parent of an autistic young person, this is something that would be a concern.

**Answer:** I'm going to pick up on a couple of words in this question. One is benefit, and the other one is detriment. You know, I think, as scientists just as is true of clinicians, and

educators we should only be doing things that are for the benefit of, of people, we shouldn't be doing anything that could be detrimental to people. And here we're talking about the autism community. To do anything that would be to the detriment of the autistic community would be unethical. And it's consultations like this where we can talk about are there any risks that the science will be detrimental? And I don't think any of us as scientists, or as researchers, would want to be associated with anything that could be detrimental. And again, forgive me for repeating it, but engagement opportunities like this, allow the researchers to check with autistic people, or in this case, with a parent, with parents of autistic kids. You know, do you agree that this is going to be of benefit rather than any risk of being to the detriment? Because we can all have our blind spots. And that's why we need the dialogue. But that's my starting point. I don't know if the others on the study team want to want to jump in. I mean, maybe whilst they're thinking I should just reiterate the Hippocratic Oath applies to medics of do no harm. But actually, that oath should apply to any professional working with a particular community. You know all of our work should be towards good not towards harm.

I think maybe from a more practical point of view. I think it's a very important question. And I'm guessing this is where the value of the Data Access Committee comes into play. And this is something that we as a team cannot resolve independently. What is benefit and what is detriment? I can imagine certain people might feel, might find value in certain aspects of research and certain people might find certain aspects of research might not have value and might cause future harm. I think realistically speaking, this is a question that we need to move conversations with within the co-creation panel. So we can come up with a Data Access Committee, which can then perhaps look through the various requests coming from researchers to then decide on what are the researchers with which we should share our data? And what's the mechanism by which the Data Access Committee can come to an agreement on which researchers should be and what data should we share.

And I just also out there just to reassure everyone, just that, from the outset, we had always, from our original ethics application, we had always built in a Data Access Committee for any data sharing within the project. No project is allowed to share any data without some oversight. We built that into our original ethics for the project. Maybe it should go without saying, but just for the benefit of people who don't know how ethics committees work within the universities, and within the NHS, those committees are a panel of people who are checking that research could do no harm. The researchers have got to examine their own studies, to make sure they couldn't be detrimental, but then there's another level of scrutiny, which is the Ethics Committee. In this case, it was NHS England, it actually also went to another Ethics Committee, which was NHS Scotland. And then there's the Health Research Authority. There's lots of levels of scrutiny, to make sure that what the scientists are doing could do no harm. But obviously why we're doing this consultation is this is the chance for autistic people and carers of autistic people to also kind of serve as an ethics committee to say, 'Could this do any harm?'

'Could that do any harm?' and to bring it to the table, bring it to the attention, so we can talk about it and if necessary, modify what's called the protocol, which is the kind of design of the study to make sure it's safe. But we wanted it to be 100% safe.

**Question:** So it says a draft FAQ document from spectrum 10k said the team has been known to lie in the past. Why can autistic people trust the aims of the study and that they're legitimate if the study team are privately suggesting they may not be trusted?

**Answer:** So this is a draft FAQ. At some point, when we were preparing the FAQ, I think what various team members did was they collated almost verbatim, various quotes that were seen on social media and commented on some of the answers that we were preparing with those of quotes from social media. So this is not a comment that came from anyone on the team but rather a comment from social media that we copy pasted into the FAQ documents just so that, we remind ourselves that this is a point that we need to address.

I was one of the people that collated feedback from social media emails, we had a lot of emails when we launched the study. And we really just wanted to collate all the feedback as much as possible to try to address those concerns, or just feedback. I would imagine that that was something that we copied and pasted from an email or social media or someone's comment. I don't remember us having written anything. But I haven't seen that document; it would be good to see it. I do agree that that's probably what happened. So it's good that we can clarify that here.

Maybe I'll just add one little thing, which is I'm picking up on the word lie, I don't know who has accused who of lying. But we're not in the business of lying. You know, we're actually in the business of transparency and honesty. We're making everything available. We're very happy to welcome you, if any of you want to come and visit us in Cambridge to have more conversations. We want we want to, we are aiming at 100% honesty, there's no other way of working that's going to be at all useful. What we're trying to do is do good science, that's for the benefit of the autism community, and other stakeholders, we've talked about who they are. But deception and lying would undermine that whole effort. So that's not relevant from our side. I don't know that this particular question, I don't know who's being accused of it, but we're not accusing anybody of lying, and we hope that other people won't accuse us of that. Because we're kind of joining in a dialogue where, like in any dialogue, you need to trust that what the other person is saying is genuine and sincere.

**Question:** Is there anything else that you want to say about the aims, why they're good aims, and why people should believe you that that's what you're aiming and not anything else, or anything else that you want to spend three minutes on?



**Answer:** So if I could just also draw attention to another statement we've released on the Autism Research Centre website is called our values. I could put the link in if you like.

[At this point in the webinar the following link was shared in the Chat:  
<https://www.autismresearchcentre.com/our-values/>]

But our values are stated really, really clearly, which is that we want to understand autism. And we want to understand the co-occurring conditions, and evaluate interventions that might provide support and alleviate any distress that autistic people might be experiencing. That's a really clear statement of our values. It relates to the previous question, which is there is no hidden agenda. We're talking to you because we're being open and direct. And we want you to do the same with us. And that's how we make progress. So we've said in our values, we will not develop a prenatal test for autism. We do not believe in preventing autism, we would stand up against that. If you, if anybody wants to doubt if we're telling the truth, there's not much we can do to change your mind. But we're asking in the context of genuine dialogue, that we trust each other.