

# Transcript of the Webinar 5 questions and answers

## Topic: Any other topics about improving or changing the Spectrum 10K study

Date of webinar: Wednesday 24<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 5 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 team said in a previous webinar they plan to relaunch the study in October. How is this not prejudicial to the potential outcome of the consultation, which might be that the majority of survey respondents think that the study should be stopped altogether?

**Answer:** If the majority of consultees in the survey said that the study should be stopped altogether, we would have to listen to that. But my understanding was the aim of the consultation, both in the survey, but also in webinars, was to see how the study could be improved, particularly listening to all stakeholders. So, naturally, the study team have been thinking towards relaunching the study, and we've even got a date in mind. Not least because we have an obligation to the funder of the study, and other agencies to deliver what they wanted us to deliver. But I hope this answers the question that we don't want to prejudice the outcome of the consultation in any way. We're wanting to hear all voices. And what we expect is that, if this, if this consultation has done what it set out to do, which is to listen to all parts of the autistic community, we might hear that diverse, diverse range of voices.

I'm not sure that we asked in the survey whether people want it to be stopped. I think we asked things such as, do you think it's ethical? Do you think it can be improved and so on? But we did want to ask, and we did want to create a space for people to share their concerns, and how those might be addressed.

**Answer consultation Co-lead:** I think that to some extent, we'll have to work towards a deadline, even if there is the possibility that it's going to come out as not doing it. But the idea of the consultation wasn't to count the number of people who are in favour or against it. This also speaks to some of the other questions. It's not a counting exercise, it wasn't an attempt to get a survey of opinions in a quantitative fashion.

On the question is the study ethical? And are there any ethical issues that we've overlooked? It is interesting that an ethics committee, that judged the original study as something they would be happy to approve, they might have different views to the consultees, so we've got an opportunity here to kind of broaden the whole concept of an ethics committee to include lots of different points of view.

**Question:** What is the planned timeline for the publication of the phase three report and a decision on the future study? When can we expect these?

**Answer from the consultation Co-leads:** This is the last webinar, but we also have two further drop-in sessions, one on data tomorrow at 12 and one on Friday at one which is that drop-in session about this anything else that anyone wants to raise. And then we are closing the study at the end of May. So basically, there's a week left for the study being open. And we need time, we've obviously been reviewing those questions, those responses that we've been reflecting on them. In fact, we've started doing our formal coding of the responses, so we can understand exactly what has been said, and what people's views and opinions are. In the meantime, we're also setting up a co-production group, which is a group of 10 people who will work with Spectrum 10K, on the detail of things that have been suggested in the survey and in the webinars, and throughout this consultation, on what should be changed and improved. So we will be working on a phase three report. But we want that to be a very clear indication of what people said. And so we can't rush that, we will be producing some top line findings, some this is what broadly has been said, but the detailed final report on phase three, we will publish as soon as we can.

**Answer:** So I want to do a proper job of the of the final report. And it might take a while, because we have to focus on getting the analysis done as quickly as possible so that we can get the co-production group underway. And the formal report will take a lot more work at polishing. So that will take longer, and I would have thought it might be autumn.

**Additional Answer:** We've got to be realistic, and we want this to be a good reflection. It's also got to be useful for the purpose it was commissioned, which is to inform changing and improving the Spectrum 10K study, so that there is a bit of a time pressure, but the published report will be ready as soon as it can be.

**Additional Answer:** Because there is ethical review on this project, we will be working with our vo-production group to discuss the points raised in these webinars and to make changes to improve Spectrum 10K. And there may be changes, there will be discussions with ethics about that. And ultimately, they will have the final say about whether things are acceptable or not. So,

we will make changes, but it will be in line with our ethics committee that we will make those decisions.

**Question:** Will a detailed report covering the results of the survey, question by question be published?

**Answer from the Consultation co-leads:** Yes, a detailed report will be published as the previous phases of this consultation produced a published report. Question by question is an interesting point. That is how we are currently coding and analysing the survey responses, but that may not be the most useful way to present the findings. So the report will be thorough, it will analyse what people have said. And as in any qualitative report it will look for key findings and that might not be best presented question by question. We don't know yet because it might. I'm not going to commit to producing a report which is question by question. It will be a transparent report, which fully and thoroughly reflects the opinions that have been shared with us during the consultation.

**Answer:** So whatever form that the report takes, nothing is going to be hidden, I want to reassure everyone in the consultation, we're not interested in hiding anything that is said. And the second thing is, when we set up the consultation, we deliberately ensured that we had voices that are critical, not just those who are supportive of the study. And actually, from our point of view, the study team, the criticism is even more valuable, because that's how we learn. Did we overlook anything? And it's our critics that will sort of raise the issues that maybe we missed. We've done our best. So I think, you can expect that when the phase three report comes out, it will include the critical views, not just the supportive ones.

**Question:** Are you going to be looking at autistic traits? In combination with their genetic and environmental factors?

**Answer:** The answer is yes. Spectrum 10k involves one big cohort are people who have filled in autistic trait measures. And they can either do that through the Spectrum 10K website. Or there may be other samples that we also use, where people have taken the AQ, the autism spectrum quotient. So we will be able to look at genes that are associated with autistic traits. And we'll also be able to look at environmental factors that are that are associated with a number of autistic traits in terms of different outcomes like well-being. It's not just about analysing the data in terms of autistic people, compared to non-autistic people, we will also look at the number of autistic traits a person has.

**Question:** I wouldn't have thought that autism is really quantifiable in degrees. But there are some things that people associate with more complex autism, like with communication challenges or learning disabilities. Will you look at those?

**Answer:** Yes, absolutely. There are lots of different questionnaires on the Spectrum 10K website. And people get a chance to describe more about their experiences. But that does include communication. There are questions about language, in terms of spoken language, or expressive language. That's not the only relevant dimension. We'll be asking questions about what kind of school you went to, whether you attended mainstream education, or were on a special needs register or in a different kind of schooling. So we will be collecting a lot of information about the breadth of people on the autism spectrum, and then analyse that in relation to both genetic and environmental factors.

**Question:** Have you finished recruiting for the Spectrum 10K study?

**Answer:** Well, the study is paused at the moment. We actually cannot recruit. When we paused the study in September 2021, recruitment stopped at that point. We are not recruiting at present.

**Question:** So if you relaunch it then you can still get new participants?

**Answer:** Yes, so we need to check with the Ethics Committee whether we can recontact people who've already signed up. I think about 4000 people signed up when it was launched in August 2021. Then we paused it in September of 2021. By the time we relaunch the study, two years will have gone by. We need to sort of get advice from the ethics committee about can we recontact those who originally signed up but obviously there'll be an opportunity for new people to sign up. And the goal, as the name suggests, is to invite 10,000 autistic people or their carers and parents to be part of it.

We're really keen that the people who did sign up, we would really like to be able to include them in the study. And obviously, we don't have a lot of the DNA samples from those people. So that is one thing that we need to check with the ethics committee is whether we can go back to them and include them, which we really hoped that we would be able to.

**Question:** Will you publish how many people took part in the consultation, both the survey and the webinars? I'm asking in case that you'll publish that [e.g.] 'the majority of respondents said, but there are only five respondents altogether'.

**Answer from Hopkins Van Mil:** We will be quite clear how many people altogether responded across the piece to the consultation, as we've done with the previous phases. We will also provide some context around that, so that it's quite clear. But I really do want to stress that this is a qualitative consultation. So we very rarely use language like the majority of respondents because it's more about patterns of views and opinions, and making sure we

reflect them very well. But I take your point, if one person said something a lot of times, as opposed to everyone agreed to that, that's a very different thing. And we'll make those sorts of subtleties clear as well.

**Question:** In the study, will it be possible to distinguish autistic people's survey data from the data of those who live with or interact meaningfully with autistic people in a way that provides meaningful insights? Even better if it were possible to distinguish findings associated with those non-autistic [people] who happily associate with autistic people and those who don't.

**Answer:** When a participant signs up to the project, they identify whether they are an autistic individual or they are not an autistic individual, or whether they are family or a carer. So we are able to distinguish.

The bit about whether they happily associate with autistic people, I hope they all happily associated. But I don't think we ask anything about the nature of their relationship. So we won't be able to answer that bit. And I suppose we should clarify that when we when we look at data from parents or carers, it's only for those autistic people who are under 16. Unless the individual signs up as a non-autistic relative, then they could also take part.

**Question:** So is that how it is that how it works? You get autistic people, and some of them will have relatives who will also do questionnaires and stuff.

**Answer:** So any autistic individuals who sign up as adults are able to invite non-autistic family members to participate as well. So they will send out an invitation and other family members can then take part if they wish. It is up to second degree relatives, so that would include an uncle or an aunt, or a cousin, first cousin, or a grandparent actually.

**Question:** We have a follow about whether the survey asks whether a study should be stopped? As it does ask whether it can be improved.

**Answer from the consultation Co-leads:** Part of that is that this is in combination with an earlier question that asks whether they think that the study is a good idea, because some people and we have actually had some answers like this, say that the study is fantastic and can't be improved. So you have to take them both together to understand what people meant.

**Answer from Spectrum 10K:** There's also an open textbox after that question, which is really what we're interested in. Because I think we ask the reasons for their answer. So if they've said no, we really are interested in in understanding why they've said no. So it's not only the previous question, but the follow up question will give us a real picture, a real taste of why they're saying no or yes. And I think it comes back down to Henrietta's point about the

usefulness of not just reporting majorities, but it's actually the content of what people's views are, that is the important thing.

There are people in the consultation who think this study is fantastic and needs no improvement. But we know that there are some people in the consultation who still feel very worried about the study. So those are the two kinds of extremes and no doubt, lots of viewpoints between those extremes. And we want to analyse all of them, we don't want to hide or bias the report in favour of anyone. So I think what Henrietta's team is experienced at doing is making sure that the breadth of those different viewpoints comes out.

**Question:** Has the funder been consulted about the changes? And the sponsor? And what were the outcomes of those discussions?

**Answer:** We have been in contact with our funder but there's been no changes to the original grant proposal. So any changes to the project that will be made will be made as part of this consultation. We have not discussed overarching changes to the project with the sponsor, we said we may do this, we may do that. But it all depends on the consultation, so until we get the feedback, there are no discussions really ongoing. And that has certainly been the case with the funder, they're just aware that of the work that we're doing as part of the consultation currently.

**Question:** So how are you going to be publishing the results of the of the findings from the study?

**Answer:** Scientists publish their findings in peer reviewed journals. And that will be during the lifetime of the study but also after it. And it tends to be scientists writing for other scientists. So there might be specialist autism research journals. And there might be other scientific journals, particularly for geneticists. But in addition, we have a commitment to also doing broader dissemination of results. So publishing non-technical summaries of findings. And that could be through a variety of outlets. New Scientist is one example of a magazine that is non-technical but reaches a wider public.

One point that would be worth considering, and also discussing, as part of the consultation and working group is the publication of lay summaries, when we do publish results, and making those available.

There's an opportunity here to really think about our sort of dissemination strategy and involve autistic people in how they would like us to communicate the results and when and what format. I mean, we often go to academic conferences, but I don't know how well attended those are by autistic people, because I've not been to one for such a long time. But there are

all sorts of different ways in which we could think about engaging with the community in the dissemination and having people involved in that process.

**Question:** Will you endeavor to publish open access?

**Answer:** Yes, so where possible, we always choose open access publications.

**Question:** Will you have ongoing engagement with the community in terms of publicity and stuff? You had advisory group when you started, do you still and will they have a role? Or will any other involvement have a role in dissemination?

**Answer:** We definitely will have an advisory group on the project, the shape of that going forward after the consultation, and the working group, is something we will discuss and decide on but there definitely will be a role.

We don't want the engagement with the autism community to end with this consultation. We want to ensure there's representation of autistic people and families, right through the lifetime of the project. So there will be an advisory group. And that group should be consulted on every aspect. So that does include dissemination.

**Question:** Just a suggestion to be mindful of the study's takeaways going beyond purely factual results, there may be some kind of messaging or PR. There seems to be an autism bandwagon in the media, which may be getting in the way of balanced and factual messaging. The message surely needs to distinguish those with severe autism from those with Asperger's. Equally myths, such as ASD people lack empathy, so can't love or have proper relationships, also need to be dispelled?

**Answer:** I think this comment, it's a suggestion really, it's to be mindful of what are the take home messages, they need to be balanced, and factual. And I think some of the other points here are also important, if celebrities are involved, is that distorting the message. So really keeping things balanced.

One of their points here is about distinguishing people with one type of autism from another. We no longer use the term Asperger's syndrome. In terms of diagnosis, we recognise people have received that diagnosis historically. But because several of the international classification systems have removed Asperger's as a part of the classification. We're now just using the term autism. But we will be distinguishing those autistic people who, for example, have learning disabilities and those who do not, or those who have language disabilities and those who do not.

And the last point here is about dispelling myths. Well, you know, we do want to ensure that myths are dispelled. So the idea that autistic people lack empathy is untrue. It's not a conclusion that's come out of our research. Empathy itself is quite complex and has at least two different parts. One is called cognitive empathy and the other is called affective empathy. And it seems as if some autistic people struggle with cognitive empathy. But it's certainly not the case that autistic people lack empathy in any global sense. So we want to play our part in dispelling myths. And we're aware that the media can distort things.

**Question:** One of your answers says Spectrum 10K don't see one group subgroup as better than another. However, previous messaging, said that the study looks into understand the broad heterogeneity within autism that ranges from learning difficulties through to talent, implying these two characteristics are on opposite ends of the spectrum and cannot coexist. So can they be trusted to explore subgroups if there are such implications?

**Answer:** We hope that you do trust our team and we are very well aware that people who are autistic and have learning disabilities can be talented. And we've worked with such individuals. And we've done studies on talent across the whole autism spectrum. I'm sure, many of you will have met autistic people who, for example, may have a learning disability, but are talented in something like music, or memory, or some other aspect of the mind. So to the main point, do we see all subgroups as equal? Absolutely, we do. Now, I'm saying that as clearly as possible. That people are people and deserve to be treated equally, it doesn't really matter what their characteristics are.

A part of this is also about being more precise in the description of a person's experience. It's not about pitting groups, it's about being clear descriptors within autism, about how a person's life is.

**Question:** What co-occurring conditions is the study looking at? How are those decided? And what about some others, various lists of others Spectrum 10K might want to consider?

**Answer:** The list of co-occurring conditions that the study will be looking at is actually quite a long list. So it includes both physical health conditions, mental health conditions, and then other neurodevelopmental disabilities. So it runs into dozens. Certainly, there are some measures that look at sensory experience as part of this part of this study. Inevitably, there'll be some co-occurring conditions that we won't have covered. We're learning about new associations all the time. But we're trying to capture as many as possible. And there is actually scope before the re-launch, to make additions, so please send them in if you feel that there's been any omission.