



Spectrum 10K Consultation

Phase 2: the Co-design

What was said about how to design an effective consultation process

An independent report

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Contents

Executive Summary	1
1. Background (Introduction)	1
2. What happened in Phase 2 (method)	1
3. What co-designers said about the consultation (results)	2
4. Recommendations (discussion)	2
1. Introduction	1
1.1 Background	1
1.2 Who is running the consultation?	1
1.3 What is the consultation process?	2
1.4 Phase 1 recommendations	2
1.5 A note about this report	3
2. What happened in Phase 2 (Method)	4
2.1 Who took part in phase 2	4
2.2 How co-designers got involved in Phase 2	5
2.3 Approach	6
2.4 A series of four workshops	6
2.5 An online space created specifically for Phase 2	8
2.6 One-to-one interviews	9
3. What co-designers said about the consultation (Results)	10
3.1 Overarching principles	10
3.2 What should be discussed	13
3.3 Who should be involved	16
3.4 Consultation methods	17
3.5 Structure and process	19
3.6 Communications	21
3.7 Timescale	23
4. Consultation recommendations (Discussion)	24
4.1 Recommendation on the consultation plan	24
4.2 Recommendation on the information needed by consultees	24
4.3 Recommendation on who should be involved in the consultation	25
4.4 Recommendations on the consultation process	25
4.5. Measuring Phase 3 success	27
Appendix: Questions and concerns to address in Phase 3	29

Executive Summary

1. Background (Introduction)

The Spectrum 10K study led by the Autism Research Centre at the University of Cambridge aims to investigate genetic and environmental factors that contribute to autism, co-occurring conditions, and the wellbeing of autistic people. Following the launch of the Spectrum 10K study in 2021 there were concerns raised by many autistic people. The Spectrum 10K team will use the findings from this consultation to inform and adapt the Spectrum 10K study, where possible.

The consultation is led jointly by:

- Hopkins Van Mil (HVM) – independent facilitators
- Lenah Buckle – Autistic co-lead
- Spectrum 10K research team from Cambridge University

The consultation is in three phases:

Phase 1: Deciding who should be involved in co-designing the consultation

Phase 2: Co-designing the consultation with autistic people

Phase 3: The consultation

This report is about the process and outcome of Phase 2.

2. What happened in Phase 2 (method)

From a pool of 429 applicants,¹ 130 were selected to be co-designers² to reflect a range of characteristics the Phase 1 participants considered important. When Phase 2 began 111 people (85% autistic) confirmed their involvement as co-designers. 19 of the original 111 decided that they couldn't commit the time taking part. Those that did take part represented a range of genders, ages, ethnicities, support needs, views, and experiences.

HVM and Lenah used a variety of qualitative methods in Phase 2: speech and text, one-to-one and in groups, live and asynchronous discussion. This was carried out in three formats:

1. Four Zoom workshops with the same 22-24 people.
2. An online space for those involved in the workshops and 79 others to contribute in their own time to activities, polls and discussions
3. One-to-one interviews with 8 co-designers who met with an HVM facilitator either on Zoom or over email.

These were supplemented with online polls using menti.com³ and polling, prioritising and multiple-choice questions using Recollective (the name for the online space).

¹ 429 participants expressed an interest in taking part in Phase 2 and Phase 3. All those people will be invited to take part in Phase 3.

² Throughout this report we describe those who took part in Phase 2 as 'co-designers'

³ www.mentimeter.com a method used for capturing people's first thoughts on a subject

3. What co-designers said about the consultation (results)

Co-designers reviewed a list of questions and concerns that have been raised about the study and added further topics the consultation should cover (listed in the appendix).

Phase 2 co-designers said that autistic people must be a majority of the consultees⁴. They should reflect diverse lived experiences and views. There should be wide advertising so all those who may wish to be involved hear about it.

The consultation design should be accessible for any autistic person who wants to take part. The consultation should use a range of methods to suit different needs.

The consultation should adopt a staggered approach, giving people time to reflect and form their opinions.

Regular updates are needed on HVM and Spectrum 10K websites and sending 'next step' emails to consultees, so they are clear what they need to do to take part in every consultation stage.

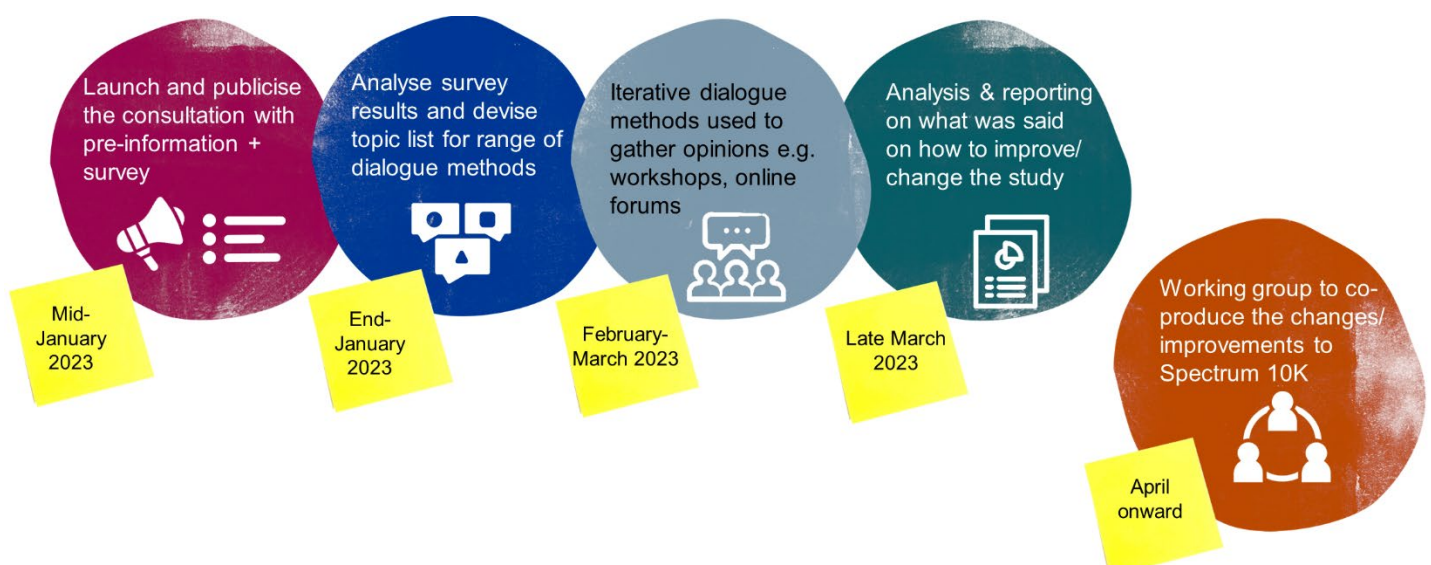
4. Recommendations (discussion)

During Phase 2 co-designers frequently spoke about points which we have grouped here as four **overarching principles**:

1. Build trust in the process
2. Make real and positive change to the Spectrum 10K study
3. Show that the consultation involves, and has been designed by, autistic people
4. Create a space for constructive discussion where people can hear, learn from and respond to a range of views and experiences.

These principles should underpin all aspects of the consultation and are reflected in the four specific recommendation areas that follow.

Recommendation 1: The consultation plan



⁴ Throughout this report we describe those who will take part in Phase 3 as 'consultees'

The consultation should take long enough that participants have an opportunity to consider all the information, develop their views, and respond. Therefore, we recommend the consultation is planned for an 8-week period from January to March. This may be followed by an optional co-production phase where specific changes to the study process and documents are made.

Recommendation 2: Information needed by consultees

Consultees need information about the Spectrum 10K study as well as the criticisms that have been raised. Information in response to straightforward factual questions that have been raised can be provided in advance of the launch of the consultation.

To the greatest extent possible within the timeframe and budget, materials and discussion topics should be produced in multiple formats (e.g. plain English, Easy Read, video).

Recommendation 3: Who should be involved in the consultation

The consultation should be primarily focused on the views of autistic people. The consultation should include a similar range of backgrounds and interests as in Phase 2. Anyone should be able to give their views, without restrictions on numbers.

Recommendation 4: The consultation process and format

The consultation should take an iterative, staggered approach with multiple formats and stages. Consultees should have multiple means of engagement (e.g. speech, text, pictures). The process should include two stages:

- A wide survey of views on all topics related to the Spectrum 10K study
- Opportunities for in-depth discussion and engagement with researchers about some topics. It is important to confront contentious topics openly and early.

Co-production

An additional co-production phase would extend the consultation process to practical changes that the co-designers want to see. The co-producers would work with the Spectrum 10K team to create the detailed change and improvements to the study (including research documents and process) set out in Phase 3.

Measuring Phase 3 success

The following points are suggested to guide how the success of the consultation could be measured. The consultation is successful if:

1. Those involved act with openness and transparency
2. Information provided is accurate, accessible and clear
3. It provides a constructive space where consultees' opinions are heard
4. It includes a balance of positive, negative and neutral aspects of autism
5. It builds trust in the study and the research team
6. It has influence on the study
7. It shares learning

1. Introduction

1.1 Background

Spectrum 10K is a research study led by the Autism Research Centre at the University of Cambridge. The study aims to investigate genetic and environmental factors that contribute to autism, co-occurring conditions, and the wellbeing of autistic people. In particular, the study aims to identify common genetic variants associated with autism, autistic traits, and chronic health conditions that occur more often in autistic people (such as epilepsy and gastro-intestinal pain).

Within a week of the study launch in August 2021, thousands of autistic people and/or their parents signed up. However, simultaneously, a number of concerns were raised. Although no breaches of the ethically approved study protocol occurred, the Spectrum 10K team decided to pause the study, with the support of the Wellcome Trust (the funders), the University of Cambridge and Cambridge & Peterborough Foundation Trust (joint sponsors), to allow time for large-scale and more diverse engagement with the autism community.

This engagement will enable the Spectrum 10K researchers to listen to and include opinions ranging from supportive to critical, discuss the complex bioethical issues surrounding the collection of DNA, allowing Spectrum 10K to learn from different perspectives, adapt the study, and re-build trust.

1.2 Who is running the consultation?

The consultation is led jointly by:

- Hopkins Van Mil
- Leneh Buckle
- Spectrum 10K

Hopkins Van Mil

[Hopkins Van Mil \(HVM\)](#) is a small social research and public engagement agency. It specialises in consultations which take time to engage with all those who need to be involved. HVM facilitates engagement so that voices are heard, learning is shared and understanding achieved. In October 2021 Hopkins Van Mil (HVM) was commissioned in a procurement process run by the Autism Research Centre at the University of Cambridge to work on the Spectrum 10K consultation. HVM's role in the consultation is to work as independent and impartial facilitators. This means we listen to and explore the perspectives of the autism community to find constructive ways forward.

Leneh Buckle

Leneh is an autistic researcher and social care trainer with long experience working productively with neurodiverse teams. Leneh joined as a co-lead of the consultation alongside HVM and Spectrum 10K following recommendations from Phase 1 that an autistic person should have this role. Leneh works closely with HVM to facilitate the consultation co-design process and to interpret and report on the outcome.

Spectrum 10K team

The consultation is overseen by the team at Cambridge to make sure that the outcome is useful, relevant, and will help to address concerns and improve the study. The Spectrum 10K team will use the findings from the consultation to inform and adapt the Spectrum 10K study.

1.3 What is the consultation process?

The Spectrum 10K consultation is facilitated by Hopkins Van Mil using co-design and co-production. Co-design and co-production are where stakeholders - the people who are or could be affected by something - work together with professionals to design and/or create something. In this case, autistic people are the stakeholders who are working together with professionals - Hopkins Van Mil with Leneh Buckle – to design and create the Spectrum 10K consultation. This means that the consultation is not designed by non-autistic researchers or 'engagement' experts, but in cooperation with autistic people from the start.

The work we are doing is in three phases. The timetable for the programme is shown in Figure 1.



Figure 1: The consultation timetable

1.4 Phase 1 recommendations

The report from Phase 1 was published in May 2022 and is available [here](#). An important recommendation from the Phase 1 discussions was to have autistic involvement at a high level to run the consultation. Because HVM did not already have someone on the team who could provide that, we ran a recruitment process to engage an [autistic co-lead](#). This freelance appointment was made in July 2022.

We also learned from our discussions in Phase 1 that people highly value a process which is co-designed with autistic people throughout. Four principles discussed in

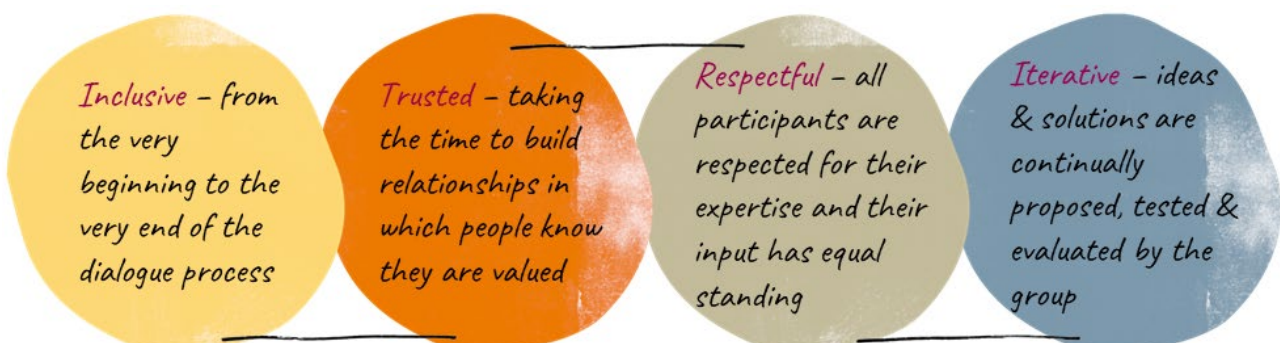


Figure 2: The principles of co-design Phase 1 co-designers highlighted

Phase 1 are therefore underpinning our work on this consultation. These are described in Figure 2.

1.5 A note about this report

This report explains what we heard from those who participated in Phase 2 processes to co-design the consultation. The majority of those who took part are autistic people. The report has been written by the HVM team with Leneh.

We have used qualitative research methods to review what people who were involved told us. We also used some quantitative methods to support this. Transcripts were created from each of the consultation methods used. These were anonymised so that no one can be traced back to the comments they made in this report. We call the people involved in Phase 2 'co-designers' and the people who will be involved in Phase 3 'consultees' throughout this report.

Qualitative research reports, including this one, do not report on the number of times something was said, but rather the strength of feeling expressed across the methods used. For this project we used grounded theory, which means we read, and re-read, the transcripts many times. We collated what was said into key themes (called codes) and from these drew out the meaning from the discussions. We chose this approach in order to have a genuinely co-designed process, rather than looking for confirmation of preconceived ideas. Throughout the report:

- Bullet points are used to summarise key points made. These mostly reflect areas of agreement and where points were made by many people across many of the groups
- Terms such as 'a few', 'several', 'some' or 'many' are used to reflect particular areas of agreement and difference

Anonymised quotations are used to highlight points made by a number of co-designers and to underline points made by a range of co-designers. These quotations are not edited so as not to distort the speaker's meaning.

2. What happened in Phase 2 (Method)

2.1 Who took part in phase 2

Who to involve in Phase 2 was drawn directly from what those who took part in Phase 1 told us. This is summarised in the [Phase 1 report](#).

It was agreed that given the budget and time available we would aim to recruit up to 150 people to Phase 2. This number would allow us to:

- Include 80-100 co-designers, given that there are always some people who cannot in the end take part due to illness and other circumstances
- Enable a comprehensive and meaningful co-design discussion

Non-autistic people with a professional interest in autism, e.g. health and care professionals or charity representatives, were not included in this phase. It was considered more important to ensure autistic people have the opportunity to have their voices heard in Phase 2. Non-autistic people, including those with a professional interest, will be invited to contribute to the consultation itself.

Phase 2 co-designers in numbers

The breakdown of co-designers who took part in Phase 2 from rural, sub-urban and urban areas all around the UK is summarised below:

Status:

- 95 autistic people, including some who had a learning disability and some who are parents of autistic children
- 16 non-autistic parents/ carers of autistic people

Gender:

- 63 women (61 cis-, 2 trans-)
- 42 men (39 cis-, 3 trans-)
- 6 non-binary people

Ethnicity

- 16 people from Black and minority ethnic communities
- 95 White British people

Age

- A range from 16 to 79

Views on autism genetic research

- 3 people completely against
- 4 against, but not completely
- 39 don't know or undecided on their view
- 37 quite supportive
- 28 wholly supportive

In Phase 2 we also asked co-designers to describe their connections to autism. The 98 co-designers who responded to this question could select multiple options.



Figure 3: Phase 2 co-designers' connection to autism.

A majority of Phase 2 co-designers are autistic people. Many of the autistic co-designers and all the non-autistic co-designers have another connection to autism through their families, friends, and wider networks.

2.2 How co-designers got involved in Phase 2

An online survey ran between May and August 2022 where people could register interest in Phase 2 and/or Phase 3 of the Spectrum 10K consultation. Respondents were also asked for demographic and health related information to ensure we included people who fit the broad representation recommended in Phase 1. The survey was launched by Spectrum 10K and Hopkins Van Mil on their websites and Twitter. It was also shared with those who had signed up to be part of the Spectrum 10K study, after the Health Research Authority gave permission.

Those who expressed interest in Phase 2 were sent a further questionnaire which asked for their preference for mode of involvement (e.g. online workshops, other online activities, one-to-one interviews). We also asked for respondents' views on genetic research for autism so that we could recruit a range of perspectives.

429 people responded to confirm they would be interested in taking part in Phase 2. Because of budget and time, it was only possible to include about 130 people in Phase 2.

A great deal of thought was given to who to involve based on the characteristics that were asked for in Phase 1. This included reviewing all the responses and grouping them according to characteristics such as age, gender, ethnicity, whether they were autistic, whether they had co-occurring conditions, and support for genetic research. Within each group, individuals were selected non-systematically. The aim was to obtain the widest possible range of backgrounds, not to get a representative sample in terms of numbers.

In making these selections, we were very mindful that nearly 300 people would be disappointed at not being selected to take part. All were sent emails thanking them for putting themselves forward and reassuring them that they would be invited to take part in the Phase 3 of the consultation.

2.3 Approach

In this section, we will describe the process of what we did with the 111 co-designers who took part in phase 2.

We mainly used qualitative methods to explore and understand what is important to the people participating. We used a variety of methods: speech and text, one-to-one and in groups, live and asynchronous discussion. This was carried out in three elements:

1. A series of workshops
2. An online space for people to contribute in their own time
3. One-to-one interviews.

These are summarised below, and more detail can be found in the appendix. Additionally, we supported the discussions with an online polling tool called menti.com⁵ and polling, prioritising and multiple-choice questions using Recollective.

Using these approaches, we asked co-designers for their thoughts on:

- Important topics for the consultation
- How to make the consultation accessible to as wide a range of people from the autism community as possible
- Other considerations for how the consultation should be done

We stressed that topics to do with the Spectrum 10K study itself, genetic research in general and more, will be welcome in the consultation itself but would not be covered in detail in Phase 2.

All co-designers received documents to give context to their discussions. These included:

- The Phase 2 agreement on working together is [here](#).
- Information about the limits of the Spectrum 10K consultation is [here](#). This specifies what the consultation can and cannot change about the study, e.g. due to time, budget and the requirements of the grant funding the study.
- The list of themes, questions and topics that were reviewed during the Phase 2 co-design phase is [here](#). These were collated from the comments and complaints following the initial launch of the study.

All those who contributed their hard work to the Phase 2 co-design were paid £20 per hour for their time.

2.4 A series of four workshops

There were 2-hour long workshops held weekly for four weeks in September and October 2022. The workshops were run by the HVM team, including the autistic co-

⁵ www.mentimeter.com a method used for capturing people's first thoughts on a subject

lead recruited for this project. In order to create an environment where all co-designers would feel free to share their thoughts and opinions, the Spectrum 10K research team were not invited to attend the workshops. The Spectrum 10K team provided a pre-recorded presentation with background about the study for the first workshop.

Each workshop in Phase 2 was attended by the same 22-24 co-designers. The majority were autistic people with 3 co-designers who were non-autistic parents/ carers of autistic people.

The workshops were held using Zoom video conferencing. Co-designers had the option to participate using speech and/or text. Before taking part in the workshops, co-designers received an emailed handbook to give information on what to expect. This was tailored to how they were taking part in the workshops (whether speech or text). Co-designers mainly worked in four sub-groups of 5-7 people supported by an HVM facilitator during the workshops. The groups were as follows:

- Autistic people working entirely in text
- A mixed group of autistic and non-autistic parents
- Two groups of autistic people who mainly used spoken word, with some text, to communicate

When not in small groups, co-designers took part in polling activities using [Mentimeter.com](https://www.mentimeter.com). These asked a range of quantitative and qualitative questions relevant to the focus of the discussion for each workshop. The results of this polling are used as illustrations for key points throughout this report.

Workshop 1, 22nd September

This workshop looked at the themes, topics and questions that have been raised about the Spectrum 10K study. The workshop included:

- An introduction to the co-design phase and its purpose
- An introduction to the Spectrum 10K study given in a recorded presentation
- Discussion on the themes, topics and questions raised about the study⁶
- Discussion on what is missing from the themes, topics and questions that should be discussed in Phase 3.

Workshop 2, 29th September

This workshop considered access, inclusion and balance within the consultation. The workshop included:

- Reminders of the purpose of the co-design phase
- Discussion on how to achieve appropriate access and inclusion for Phase 3
- Discussion on how to achieve a balance across the themes, topics and questions that should be discussed in Phase 3.

Workshop 3, 6th October

The third workshop focused on co-designers' opinions on trust and transparency, and the contents and structure of the consultation. The workshop included:

- A presentation: What is a consultation?
- Exploring elements of the consultation that are important
- Discussions on trust and transparency in the consultation

⁶ The document summarising the themes, topics and questions raised after the Spectrum 10K study was launched is available [here](#)

- Consideration of the structure of Phase 3, including which methods should be used to understand people's views on Spectrum 10K.

Workshop 4, 13th October

The final workshop brought all the thinking together. The workshop included:

- A reminder of all that we discussed so far
- Consideration of the balance of views in the consultation
- Reflections on reporting on the findings of the consultation
- A final discussion on expectations and hopes for the consultation, including creating a safe study space.

2.5 An online space created specifically for Phase 2

Over four weeks we used the online space, called Recollective, to extend the discussions by the workshop co-designers. We also used it to gain the opinions of an additional 79 autistic people. The online space was only available to these co-designers and the HVM team. It included:

- A home page to explain the purpose of the co-design phase and to tell people what they would be doing in the space
- An activities page to answer questions about the design of the consultation
- A discussion area where co-designers could raise their own topics.

The questions asked and the points covered in the online space mirrored the workshop topics.

Activity Title	Dates	Participation
Questions about your connection to autism	Sep 16 - Oct 31	81 / 86 (94%)
Questions about the themes, topics and questions for Phase 3	Sep 16 - Oct 13	18 / 22 (81%)
Questions about the themes, topics and questions for Phase 3	Sep 16 - Oct 31	75 / 86 (87%)
An introduction to working together	Sep 22 - Oct 31	18 / 22 (81%)
Review the notes from last week's small discussions	Sep 28 - Oct 31	17 / 22 (77%)
Some priorities for the Phase 3 consultation	Sep 28 - Oct 31	62 / 86 (72%)

Figure 4: Activities in the online space.

2.6 One-to-one interviews

Interviews were conducted in Phase 2 with seven autistic people using Zoom and 1 person via an email discussion. The questions asked and the points covered in the interviews mirrored the workshop topics.

3. What co-designers said about the consultation (Results)

3.1 Overarching principles

During Phase 2 co-designers frequently spoke about points which we have grouped here as four overarching principles. Co-designers believe that these principles should be applied throughout the consultation. They are summarised in Figure 5 and explained in the text below it.



Figure 5: the principles developed or the consultation

1. Build trust in the process

Given the concerns raised about Spectrum 10K, co-designers throughout Phase 2 emphasised the importance of building trust in the consultation process. This ties in to the concern that those who have called for a boycott of Spectrum 10K will refuse to take part in the consultation. This would be disappointing for Phase 2 co-designers, who want to ensure that all views on Spectrum 10K are considered, including those who have been critical of the study.

The involvement of the Spectrum 10K research team is seen as important by many co-designers, even 'vital' by some. They recommend there are opportunities in the consultation for the research team to:

- Hear directly from autistic people about their concerns in relation to the study, e.g. to test their assumptions about what matters to autistic people
- Share their perspectives on why they consider the study essential
- Provide information on the study and answer questions

And for consultees to:

- Have direct interaction with the research team to put a face to the researchers who currently feel somewhat mysterious
- Understand the history of the research team in relation to understanding autism.

Co-designers also consider that it will be helpful in building trust in the study if it is clear who the funders of the study are and if there is greater understanding of the rationale for funding the study.

“I think actually having interactions with [researchers] before and knowing that they’re not just some mysterious organisation. I think that would benefit the people a lot anyway. I think the less shadowy a figure they are, in the sense that if people can actually see faces for it, I think that’s going to build trust.”

Transparency is seen as essential to building trust in the consultation process and the study.

“I think it’s all about transparency. People need to know what’s going on and have as much information as possible about the study and its goals.”

Transparency includes being clear about:

- Who is involved in the research
- Who is funding the research
- How the funding could influence the study outcomes
- What the study aims and goals are

Trust cannot be built if people perceive there to be any hidden information or agendas within the consultation. Co-designers want to know that this consultation is a genuine attempt to improve the study. They believe that showing that this consultation is different to those which appear to be making an insincere attempt to gain people’s views is important.

“I have taken part in several government consultations, and they never meet any of the criteria (we heard about in the presentation on what is a consultation). They’re just doing it to jump through hoops and pretend they’ve consulted people, but they’ve clearly already decided what to do.”

Independence is also a key word used by co-designers. They highly value that HVM and Leneh Buckle are co-designing and delivering the consultation, independently of Spectrum 10K. It is particularly important that this team includes an autistic co-lead.

Underlying these points is the belief expressed by co-designers that trust takes time to build and is helped by co-designers getting to know who they are working with, including the co-leads, to give people the confidence to express their views. As one participant put it,

“The whole process of being consulted would be improved by having some sort of opportunity to meet the person that was going to interview me, prior to that. I think that would make it easier to talk and probably reduce my anxiety.”

2. Make real and positive change to the Spectrum 10K study

A key principle for the consultation is that those involved in the consultation, particularly autistic people, can have real influence on the study. It is very important to co-designers that the consultation is, and is widely perceived to be, meaningful.

Tied to this is the need to know, in advance of taking part in the consultation, what can be influenced, e.g. some elements of the baseline questionnaire, and what cannot be changed, e.g. that the study collects DNA.

To achieve a clear demonstration of how their views have influenced changes to the study, consultees expect to receive feedback. As such, when the Phase 3 report is published, they would expect a statement from Spectrum 10K on what has been done to improve the study.

“I think feedback helps to give people the sense that they’re in a transparent process because it closes the loop. A question has been asked, a response has been given and we can observe the ongoing work... and see that our points have been picked up.”

3. Show that the consultation involves, and has been designed by, autistic people

Demonstrating that the consultation has been co-designed by autistic people is a foundation stone for co-designers. They suggest that clarity on who has been involved in Phase 2 will help to overcome the fears of those who have previously been highly critical of the study.

“Make it quite clear that a lot of us involved in Phase 2 are autistic. Then that’s like a way to build trust, if people are a bit more sceptical.”

Equally important is that those involved in the consultation are in the majority autistic people.

4. Create a space for constructive discussion where people can hear, learn from and respond to a range of views

The fourth principle that co-designers stress is to ensure diverse opinions are sought and heard in the consultation. This will ensure that different experiences are taken into account e.g. people’s route to a diagnosis, their age, or their view of genetic research. This includes making a space for people to share highly critical views of Spectrum 10K. Some were concerned that critics of the study would choose not to be involved in the consultation because they are too angry and mistrustful to take part. Co-designers in Phase 2 want to know that space is made for these views.

“(People) need to be allowed to be angry and express their anger, but in a way that holds that and allows them to express it so that they don’t feel like they’re being shut down.”

Creating a consultation that enables constructive discussion is important. This includes hearing from people whose views are different to your own as a valuable tool to:

- Develop new thinking and new ideas
- Think creatively and out of the box
- Reconsider views based on what others have said
- Enable people who find it easier to build on the thoughts of others rather than start from scratch to take part

- Recognise that autism is different for everyone, and this range of perspectives needs to be aired to inform what can be improved about the study.

There is recognition that the consultation must be a safe space for people to air their views. This includes having clear guidance for the discussion and ensuring that the independent and expert facilitation allows all views to be expressed without causing distress.

“It’s so easy to take things personally or to be defensive, particularly when it’s either about yourself or your identity, about your own existence, or about someone you love’s existence and their right to exist. As such it is a topic that has to be handled very carefully.”

3.2 What should be discussed

During Phase 2 we asked co-designers to comment on five discussion areas. These are the themes, concerns and questions, collated by Spectrum 10K, that have already been raised about the study. As a result of these discussions, HVM and Leneh have created a plan for addressing all issues during Phase 3.

The themes listed are:

- General information about Spectrum 10K
- Concerns related to curing or preventing autism
- Issues raised about data
- Inclusion of children, plus adults without capacity to consent to participate
- Community involvement.

Further details about the questions and concerns under each of these headings can be found in [this document](#).

We asked co-designers to suggest what, if any, issues might be missing, either sitting within or outside the above themes. We found huge breadth and depth to the topics that Phase 2 co-designers would like to see discussed during the consultation. Topics raised can be broadly grouped around four aspects to the study: its background, aims, processes and outcomes. Key questions under each of these are outlined below. This section ends with the points raised about prioritising these topics.

Study Background

The co-designers felt it was important to have information and discussion about the following:

- Information about the study’s funding, including all the possible sources, their motivations, and their origins (countries).
- Information about the researchers, their backgrounds, and their motives for conducting the study. They are particularly interested in whether anyone stands to gain financially from the outcome of the study, or can have undue influence e.g., an influence which could cause harm, bias the results, move towards an outcome which is not supported, on how the study is conducted.
- How the study relates to other studies of autism genetics.
- Understanding the non-negotiable aspects of the study.

Aims

It is essential to address the criticisms and perceived problems with Spectrum 10K. In particular, co-designers want to address the links between aims to cure and prevent autism, eugenics and genetic research, both past and present. They also want:

- In conversation with the Health Research Authority (HRA), to understand the rationale behind the original ethics approval made by the HRA's Research Ethics Committee (REC).
- For Spectrum 10K to include more on wellbeing, including co-occurring conditions and factors – including social ones – that may protect against things that commonly have a negative impact on autistic people's health.
- To know how the study will consider positive aspects of autism and the lived experience of autistic people and their families.

Processes

Phase 2 co-designers want to know:

- When the study will restart
- How long it will take to complete once it has restarted

They also want to ensure that the following topics are included:

- Issues surrounding diversity and intersectionality
- Consent and capacity issues, including capacity assessment, gaining assent
- Understanding data privacy and security issues such as anonymisation and identifiable data, sample storage and what will happen to those samples collected before Spectrum 10K was paused
- Wider issues around privacy such as access to and accuracy of medical records
- The extent to which the DNA from family members will be included in the study

Study outcomes and beyond

The study outcomes are important to co-designers and can't be easily separated from a discussion on the consultation. Discussion areas for the consultation under this heading are:



Topics surrounding future uses of the data, including how this relates to consent and withdrawal, and the Data Committee Steering Group



Gaining a better understanding of the study's aims and how it will be used to improve the lives of autistic people. Will it have any social outcomes?



The potential for commercial applications - and understanding who would benefit from them.



The potential for diagnostic tests and prenatal diagnosis, and whether there are any safeguards against this.

Topic prioritisation

Given the range of topics that co-designers wished to see included in the consultation, we asked quantitative questions to understand how they would like to prioritise the original themes and new topics.

In the answers to these survey questions we found that co-designers felt it is important to discuss contentious issues early on in the consultation. We therefore asked them to rank what they believe are the most contentious of the five themes. Their response is set out in Figure 6.

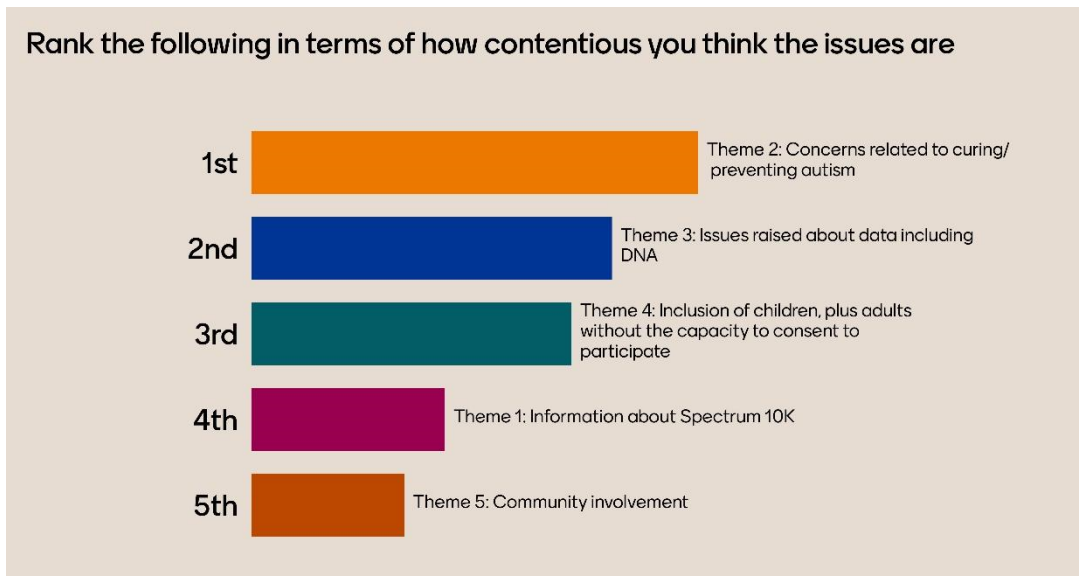


Figure 6: the most and least contentious issues

Co-designers were also asked which, of the new subjects that co-designers wanted to include in the list of consultation topics, are a priority (Figure 7). 23% of the 66 co-designers who responded to this question said topics of transparency and trust in Spectrum 10K are a priority. This included topics such as the motivations of researchers and funders of the study and reviewing what had gone wrong during the first launch process in order not to repeat the mistakes of the past. Clarity on the goals and aims of Spectrum 10K is also seen as an important priority in Phase 3.

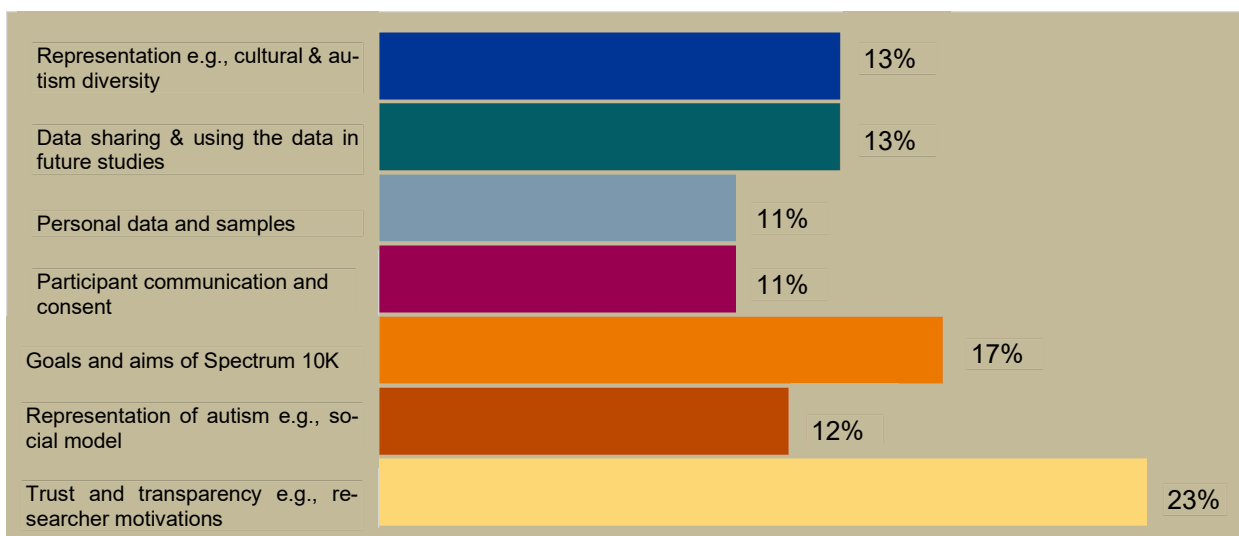


Figure 7: priorities for discussion in the consultation when considering the new topics and themes raised by co-designers

3.3 Who should be involved

Phase 2 co-designers said that autistic people must be the priority group in the consultation and be the majority of consultees. The design of the consultation should aim for any autistic person who wants to take part to be able to. This means being clearly inclusive of different diagnoses and ways of identifying with autism, as well as taking efforts to make the consultation accessible to as many autistic people as possible. There is an expectation for diversity in both the lived experiences and views of those being consulted.

“I think it’s probably blindingly obvious but that people that are autistic must be at the absolute core... I don’t see the value if it is not fundamentally centred on the experience of autistic people because really, we’re the only people that really know how it feels.”

Diagnosis

The design of the consultation does not need to place major emphasis on diagnosis. Co-designers think that the consultation should operate with an inclusive definition of autism – including those who are awaiting diagnosis or who are self-diagnosed, for instance – rather than for it to distinguish between those with and those without a formal diagnosis.

Critics

Autistic people who have been most critical of the Spectrum 10K study must be invited to take part in the consultation and offered meaningful opportunities to voice their concerns. This will involve approaching them directly, demonstrating how important their views are in changing and improving the study, and providing assurance that they are welcome to take part.

Demographics

Overall, the consultation should engage a demographically diverse group of people from across the UK. In particular, Phase 2 co-designers mentioned the importance of reaching those with first languages other than English, those based in rural areas, who may be less likely to have received a formal diagnosis, those in older age groups, who may also be less likely to have received a formal diagnosis and/or be more socially or technologically isolated.

Non-autistic people

Phase 2 co-designers mostly consider it beneficial for certain non-autistic people to participate in the consultation. Broadly, they referenced the families of autistic people and professionals already involved part of the lives of autistic people. The perspectives of parents and close family members are considered significant by many co-designers. It is also envisaged that involving parents and family members will make the consultation more accessible to autistic people who are non-verbal. Occupational perspectives that co-designers would like to see contribute to the consultation include those from medical and mental health professions and those working in education, including SENCos. These roles are suggested partly based on impressions their insight will be informative, but also partly based on the notion these professionals can

learn from autistic people during the process. Some co-designers also thought employers should be included in the consultation as a means of raising awareness in wider society about autism.

Spectrum 10K study team

Phase 2 co-designers generally agree the Spectrum 10K study team should have a role in the consultation process. The study team's presence is seen as indicative of their willingness to learn from the consultation first hand. Co-designers also express interest in understanding what's at stake from the point of view of running the study. Many co-designers would like to engage the study team in conversation or have a 'direct line' to ask questions of them. However, some co-designers are cautious about involving them in workshop discussions and share concerns about influence, privacy and the feeling of being observed.

Exclusion

Phase 2 co-designers cite rare instances in which stakeholders ought to be prevented from contributing to the consultation. For some (but not all) co-designers this includes excluding anyone advocating for a cure for autism. There is also concern that pharmaceutical companies or anyone else with a clear financial conflict of interest should not be included in the consultation.

Weighting different views

Phase 2 co-designers express concern about different views being given too much or too little weight during the consultation. Some co-designers share the concern that non-autistic parents of autistic people might have too much influence over the consultation. This concern is rooted in the widely held view that the views of autistic people must be most prominent. Some co-designers are also concerned that those who are most critical of the Spectrum 10K study may overly influence the way in which discussion unfolds at the expense of those who are more uncertain in their views.

"I think I do believe everybody should have some sort of say and some sort of access, but it's ensuring that people don't dominate or, you know, that nobody's excluded because of the way somebody else is behaving."

3.4 Consultation methods

In addition to the overarching principles previously described, co-designers discussed specific methods that should be engaged in the consultation.

Methods that vary in depth of involvement

Co-designers were clear that they had a strong preference for the consultation to use a range of methods to understand the opinions of consultees in Phase 3. They feel that using such a range of methods will enable the issues to be explored in the level of detail required for a meaningful consultation.

"I'd be really disappointed if I got to the consultation, and it was literally just a few multiple-choice questions. I'd think, 'Well this is kind of pointless'. We need to give an honest opinion and not just do a tick-box exercise."

We discussed a range of options for taking part in the consultation. Co-designers expressed a strong preference for surveys as a format when combined with other formats such as workshops, interviews, live text chat and an online space for people to respond in their own time. It was suggested that a survey should be the starting point for Phase 3, giving people the opportunity to suggest which topics should be discussed in more depth in workshops and online forums. It can be seen in Figure 8 that 46% of co-designers felt that surveys should be a significant element of Phase 3.

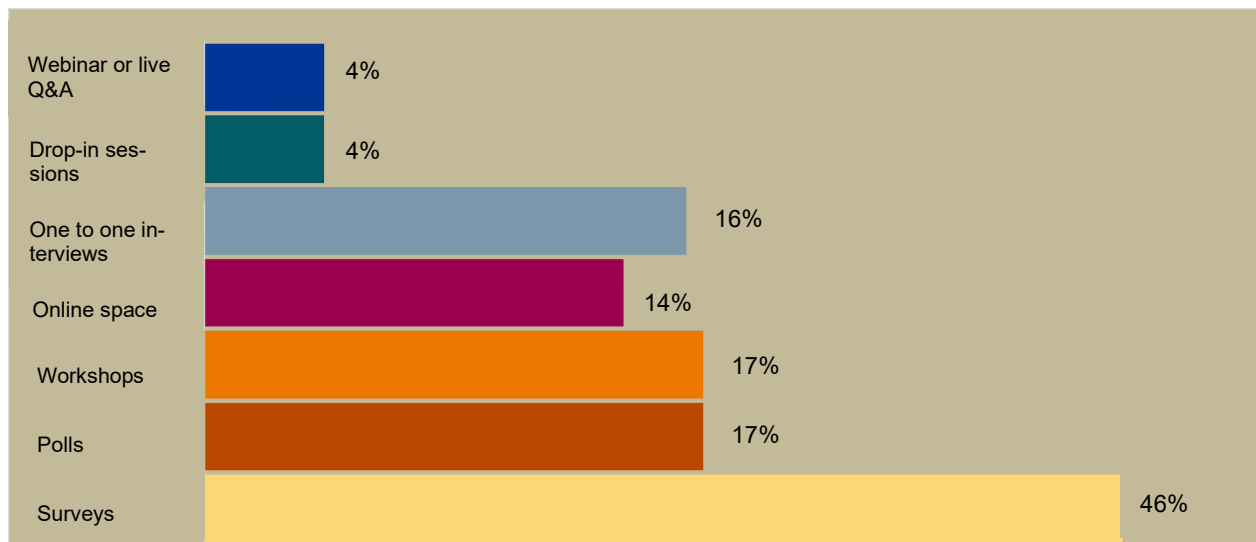


Figure 8: main methods selected for consultation (co-designers could select up to 3)

Co-designers expressed an eagerness for enabling people to take part in ways that suit their needs, interests and personal preference. For some people, a short survey with multiple choice tick boxes will be enough. It will also retain their interest and be manageable. For others, a dialogue in which they can share views and express opinions, e.g. in workshops or an online space, is more appropriate.

“I would say the key fact is that, you know, autistic people, we’re all different, and there’s no one solution for everybody. So I think for me, it was the idea of making the ways that you can access the consultation as numerous as possible.”

Methods that are inclusive of highly varied autistic needs

Co-designers said that they found Phase 2 to have been inclusive and supportive of their needs. Some shared powerful messages on what their involvement as co-designers had meant to them.

“Thanks for listening you have given me my voice back. I no longer feel isolated and lonely in my autistic wilderness.”

Some want to make sure the consultation uses better tools to enable consultees to process information. They want the inclusive approach to continue and the accessibility to improve,

“Autism for me means more detailed explanations and longer processing time. I’m not sure I fully understood the consultation aims and methods until much nearer the end of the question phase meaning I didn’t really know how to answer the questions.”

This will benefit not only those that take part, but others who learn from the consultation and, potentially the study.

“It was evident that this co-design had been designed in a way to make things easier for autistic people. Wider society need to learn how to be inclusive like this project has been.”

Some specific suggestions included adaptations for autistic processing, such as:

- Sharing information before consultees are asked for their opinions
- Providing information to consultees in Easy Read and Plain English formats
- Short video clips to explain elements of the Spectrum 10K study
- Audio clips for consultees who prefer to listen to information than to read it
- Where possible, using methods that can engage consultees who speak few or no words e.g. art based responses
- Including text only discussions, for example, having a text-based group in workshops as was used Phase 2
- Consider how to minimise visual stress when sharing information on the page or screen, such as by minimising bright colours, busy backgrounds or patterns
- Have quiet spaces, including a quiet space on Zoom, for consultees to take time out as necessary
- Accepting recorded responses from consultees to surveys and online activities
- Enabling anonymous contributions to reduce anxiety in expressing views which might not be shared by others
- British Sign Language (BSL) interpretation in workshops

“Just because somebody might find it difficult to express themselves verbally doesn’t mean that they don’t have a high degree of understanding, and there are other ways to get their message across. So just to make sure that they have an opportunity to contribute and their voices aren’t dismissed because they’re not able to speak or type.”

3.5 Structure and process

Practical suggestions were made about the structure and process of Phase 3.

Leadership and direction of the consultation

Including independent co-leads working with Spectrum 10K to conduct the consultation and report on its findings will help to mitigate the effect of unintended bias in the conduct or reporting of the consultation.

“It should be reported by an independent body otherwise it is a bit like spell checking your own homework and obvious errors and biases will be missed.”

Digestible sections

Co-designers found the format of Phase 2 productive. It took place over a 6-week period, allowing people to discuss and reflect on the issues in manageable chunks and in their own time. Adopting a similar approach would help those involved in the consultation to allow their thinking to develop, and their opinions to form over time. It will enable people to become familiar with each of the topics in manageable ways before sharing their opinions. It will allow people to feel less anxiety about taking part as they are fully prepared for each part they engage with. They agree that having bite-sized pieces of information to review throughout the consultation would be useful for many consultees.

Progress in complexity/depth

Co-designers would like the consultation to use a staggered approach, giving people time to reflect and form their opinions. They believe that using quantitative and qualitative techniques will facilitate this. For example:



Use polls or short surveys for simple 'yes/no' answers which are straightforward to answer.



Use questionnaires to understand which of the issues about Spectrum 10K study are more controversial



Use more qualitative and dialogue techniques to discuss the most controversial issues



Discuss the most controversial issues first to demonstrate that people's voices are being heard on what matters to them

'Keep consultees informed' was a key message in Phase 2. This includes having regular updates on HVM and Spectrum 10K websites and sending 'next step' emails to consultees, so they are clear what they need to do to take part in every consultation stage.

Keep consultees informed



It is important that consultees can always see where they are in the consultation process, even if they are currently focused on one specific topic or activity. A process map with 'you are here' available at all times is recommended.



"I do think it is important that you can see what you will be involved (where you are) in every section and overall before you start something new."

Adopting a staggered approach will also allow for the selection of the topics that need the most attention for more involved dialogue processes. Those issues that are more readily addressed, e.g. with factual answers from the Spectrum 10K team, will then not occupy inordinate resources.

All co-designers said the more controversial issues should be discussed first to give them time.

“You are going to have to tackle those ethical things early on because people will not engage with the process unless they feel those have been dealt with.”

Flexibility and choice

Co-designers want the consultation to be as inclusive as possible. Consultees may feel they can only meaningfully contribute to some activities or topics and not others. This approach allows for consultees to decide how to spend their personal time and efforts. It is felt that giving choice as to what they engage with and how they engage with it is essential. For example, some people may wish to take part in live text chat, others only in their own time. Some may need to work with Easy Read materials or using drawing or other visual means of expression. As wide a range of accessible methods for taking part as possible should be available.

Co-designers are also conscious of the need to minimise anxiety for those taking part in the consultation. They stress that those involved in Phase 3 should not find the process overwhelming. They propose that the consultation should always default to the simplest method that can be used to gain the required opinions. They suggest that allowing people the flexibility to change how they take part as they go along will be helpful. For example, one participant explained that thinking about taking part in a workshop or an interview could be very stressful. It would be helpful in that situation to be able to switch to answering a survey in your own time rather than attending the workshop or interview.

3.6 Communications

This section looks at two main discussion areas that emerge from reviewing what was said in Phase 2:

- Publicising Phase 3
- Communicating well throughout Phase 3

In addition, Phase 2 co-designers also spoke about how to publicise the Spectrum 10K study once it has been improved. We anticipate this will form part of the discussions in the consultation and we have not included this commentary in this report.

How to publicise Phase 3

Tell everyone who might want to take part about the consultation

It is essential to Phase 2 co-designers that all those who might want to take part in the consultation hear about it. Co-designers are ambitious for how the consultation should be promoted. Some propose use of social media to advertise the consultation. However, some co-designers also express caution because not everyone is willing or able to engage with social media.

Tell everyone who might want to take part about the consultation



“Social media is a good way to get a large proportion of the population but myself, and most of my family, don’t actually use social media. So you would need another method to get the message across.”

Some co-designers said that a marketing strategy should be developed to promote the consultation. A range of mechanisms to share information about Phase 3 were proposed by co-designers. These include:

- Workplace promotion e.g. through Equality, Diversity & Inclusion (ED&I) mechanisms and, for example, workplace autism and neurodiverse networks
- Working with education and higher education organisations so that teachers and SENCOs, for example, can cascade the information including to pupils, parent groups and students
- Through local NHS trusts, particularly those that have lists of autistic people in their area, as well as doctors' surgeries, hospitals and places where autistic people receive support
- General information services such as libraries, parenting magazines and websites
- On HVM and Spectrum 10K websites and social media platforms, as well as websites and forums of autism charities

"Information needs to be everywhere because autistic people are everywhere."

429 people have already signed up to take part in the consultation, having responded to the HVM survey in the summer of 2022.

Communicating well throughout Phase 3

Thinking about how to communicate well throughout the consultation period is seen as an important aspect of the consultation design. This should include:



Clear information about the process, the goals and what can and cannot change about the study – plus that the consultation results will inform real change to it



A range of formats to maximise accessibility, e.g. Easy Read, Plain English and audio/ video



Being clear about what autistic people have asked to be addressed in the consultation



Honest, fair and objective reporting of what Phase 3 consultees say about changing and improving the study



Sharing the outcome with all those who have taken part, and allowing an opportunity for comments on the report



Transparency about any conflicts of interest in the conduct and outcome of the consultation

Co-designers also want a statement from Spectrum 10K after the Phase 3 report is published, to share what has changed about the study as a result of the opinions expressed in Phase 3.

“Make it clear once the consultation is done what has been used to change the research and if something hasn’t been used, give the reason why.”

3.7 Timescale

The main message from co-designers on the consultation timescales is ‘Take time, but not too long’. As we have seen throughout this report, the consultation must be meaningful and staggered, giving time for consultees to digest information and to develop their opinions on the topics. However, co-designers are aware that taking too long to consult could be draining for those involved. A few co-designers wanted the consultation to take a long time (e.g. over a year), but many agreed in discussions during Phase 2 that this is not necessary if Phase 3 takes a multi-format and inclusive approach. Taking two-three months for the consultation is a reasonable timescale for many co-designers.



4. Consultation recommendations (Discussion)

In this section, we set out recommendations for delivering the Spectrum 10K consultation. These are based on the opinions shared in Phase 2. What co-designers said about the consultation is analysed and summarised by Leneh and HVM.

4.1 Recommendation on the consultation plan

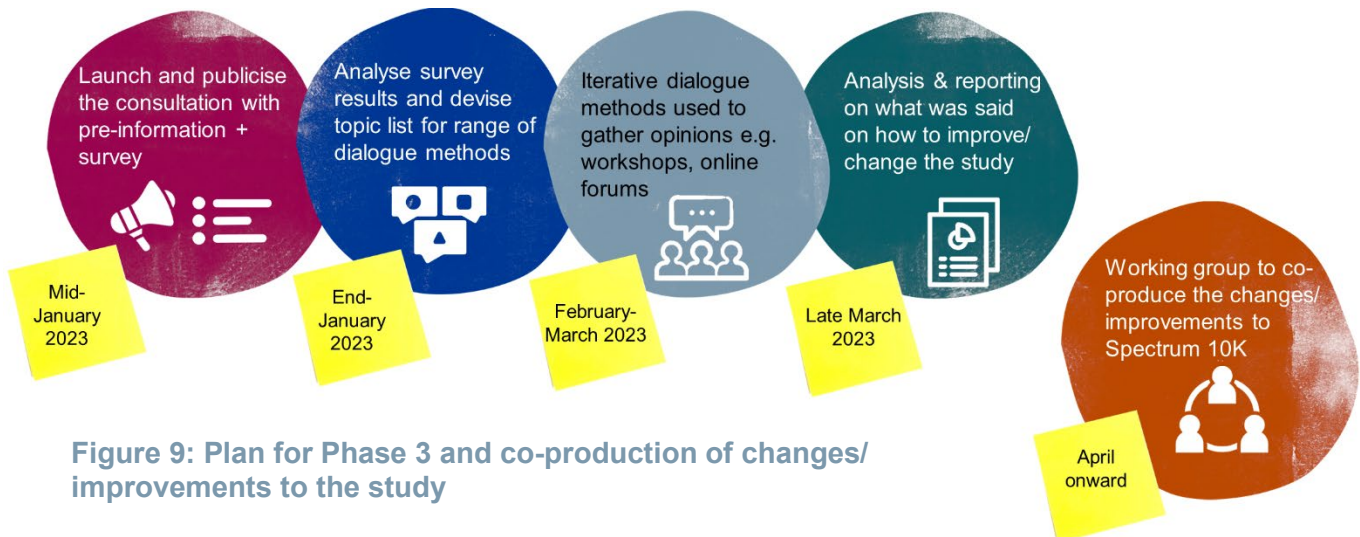


Figure 9: Plan for Phase 3 and co-production of changes/improvements to the study

4.2 Recommendation on the information needed by consultees

What consultees will need to take part in the consultation is grouped under two headings:

- Information provided by Spectrum 10K
- Information from others with an interest in Spectrum 10K

A full list of recommended topics for the consultation can be found in the Appendix. This list was derived from the [themes](#) document provided by Spectrum 10K at the outset of Phase 2 with additional questions suggested by the co-designers. These topics are rated on a scale of 1-4 based on the strength of feeling and complexity of the topic, as follows:

1. Those likely to be resolved with a simple answer from Spectrum 10K e.g. 'Who are the funders of the study?' or 'What is meant by assent?'
2. Questions with factual answers, but the topics are more complex and might also give rise to follow-up questions
3. Indicates concerns where discussion is likely to be warranted
4. Denotes some of the most contentious issues that should be discussed as a priority.

We recommend that the Spectrum 10K study team consider these topics and aim to provide factual answers where applicable to be included with background information at the launch of Phase 3.

Information provided by Spectrum 10K

Phase 2 co-designers expect to review a comprehensive set of information provided by the Spectrum 10K team in Phase 3. This includes all the information shared in

Phase 2 (available [here](#)) and information supplied to Spectrum 10K participants such as the:

- Participant information Sheet
- Consent form
- Baseline questionnaire.

It also includes background information on Spectrum 10K such as:

- A clear statement of the study aims, objectives and planned outcomes
- Materials used to advertise the study
- Original grant application
- All documents associated with ethics approval.

Information from others with an interest in Spectrum 10K

This will include, for example, statements from:

- Critics of Spectrum 10K
- The Health Research Authority.

Information, where possible, should be available in summary form including video clips, Easy Read formats and in Plain English so that consultees can review the materials in ways that suit their needs.

4.3 Recommendation on who should be involved in the consultation

Phase 2 co-designers are clear that Phase 3 must be inclusive. It must enable all those who wish to share their opinions on how to improve and change the Spectrum 10K study to take part. The majority of participants should be autistic people, with non-autistic people included who have connections to autistic people e.g. family members, mental health professionals, teachers and support workers. It is important to co-designers that those with learning disabilities and those with communication difficulties can take part in the consultation. Methods will reflect this need including having formats which ask concrete questions, allow responses in a variety of formats, and by specifically seeking to include parents/carers of autistic people who use few or no words.

4.4 Recommendations on the consultation process

The need for an iterative, staggered approach to the consultation was expressed by Phase 2 co-designers. They said that it is important to give time for people to consider their responses, to deal with controversial issues, and build trust in the consultation.

A two-stage consultation process is recommended:



1. The **consultation is launched with a survey** which includes single answer, multiple choice and free text response formats. The survey will

- Ask demographic questions to ensure the consultation is reaching the inclusive audience required for Phase 3

- Include tick box, multiple choice and open text response formats
- Have the facility for consultees to choose which topics they wish to respond to
- Give options for the prioritisation of topics e.g. which require discussion, which require information, which require more time to consider.

The survey will give space for qualitative responses to the topics so that consultees can share their opinions. It will also enable them to narrow down the range of discussion topics, and to define the topics for discussion in the next stage.

This stage is widely advertised.



2. The next stage of the consultation is a series of **topic-based discussions**. This dialogue will include a multi-format approach with consultees being able to sign up to the format that is appropriate for their needs and for the topics that interest them. Each of them would focus on the topics and questions that have been gathered in the survey. Formats include:

- One-hour facilitated online question and answer (Q&A) and discussion sessions, allowing topics to be revisited in future online live sessions as needed to conclude the discussions
- One-to-one topic-based interviews
- Two-day moderated online forum Q&A and discussion in consultees' own time
- Polls in the live online Q&A sessions and the online forums.

The number of participants will not be limited to fulfil the co-designers requirement for an inclusive consultation. Consultees will not be paid for their participation as this would make a wide-spread (potentially with more than a thousand consultees) consultation impossible to fund within the Spectrum 10K consultation budget. Consultees are being given the opportunity, if they choose to, to share their opinions on Spectrum 10K.

Following these stages the co-designers, HVM, Lenah Buckle and Spectrum 10K, will analyse the findings and produce the Phase 3 consultation report. This will be published.

Co-production

We recommend that co-production is the next step in this process. This would bring a small working group together (up to 12 co-producers). The co-producers, who should be autistic people, will be paid for their time to work with Spectrum 10K to create the detailed change and improvements to the study (including research documents and process) set out in Phase 3. This process is likely to include:

- Up to four facilitated co-production workshops
- An online space for discussing detailed points in co-producers own time
- Polls and surveys as required
- Individual engagement, e.g. interviews, for under-represented groups who may not be able to access the above methods.

In each of these elements (the survey, the topic based discussions and the co-production working group) materials and discussion topics would be produced in Plain English, Easy Read and other accessible formats including video and audio clips. Co-producers will be able to engage with the process using speech, text, video, or individual methods.

This co-produced phase would result in a report setting out all the changes proposed to Spectrum 10K followed by a 'you said this, we have done this' response from Spectrum 10K.

4.5. *Measuring Phase 3 success*

During Phase 2, we asked co-designers to share their hopes and fears for how the consultation is run and what it can achieve. We have drawn out the following points from these discussions to guide how the success of the consultation could be measured.



1. Transparent

The consultation is considered transparent and those who take part are clear about the process in which they are involved.



2. Accurate, accessible and clear information

Information provided about the Spectrum 10K study is accurate, accessible and in suitable level of detail.



3. A constructive space where consultees' opinions are heard

Those who take part feel listened to, with space for differences of opinion including those who are critical of the study.



4. A balance between aspects of autism

There is a balance struck between discussing the positive aspects of autism, alongside discussions on where more support is needed, for example, with co-occurring conditions.



5. Trust is built

The consultation builds greater trust in the Spectrum 10K study and its team, so that the study can resume.



6. A consultation with influence

The consultation influences the way in which the study moves forward, with the Spectrum 10K study team responding to and acting upon points that are raised. This could include responding to criticisms made of the study and/ or to novel ideas or suggestions made by consultees.



7. A consultation that shares its learning

The consultation itself is recognised as a significant opportunity through which people can learn more about autism. It is hoped that

the consultation may help to shape the design and conduct of research studies for the benefit of autistic people more widely, including how to make them more accessible.

“I’ve said this before, and I think I’ve probably said it in other weeks as well but (it is important) that this is actually a meaningful consultation process, and it is actually going to influence... I’m not entirely sure what I want to influence but I want to have the opportunity to be able to give my views, you know, and for everybody else as well.”

Appendix: Questions and concerns to address in Phase 3

Questions and topics taken from the themes document are in blue

Additional questions and topics from Phase 2 co-design are in red

“Anticipated depth” is the degree to which the co-leads feel the question or concern is likely to be satisfied with a simple, factual answer. These topics are rated on a scale of 1-4 based on the strength of feeling and complexity of the topic, as follows:

1. Those likely to be resolved with a simple answer from Spectrum 10K e.g. ‘Who are the funders of the study?’ or ‘What is meant by assent?’
2. Questions with factual answers, but the topics are more complex and might also give rise to follow-up questions
3. Indicates concerns where discussion is likely to be warranted
4. Denotes some of the most contentious issues that should be discussed as a priority.

Question or concern	Anticipated depth
Topic: Background to the study	
Funding	
Who is funding Spectrum 10K?	1
Is there any funding from the United States?	1
Any other countries?	1
Who will benefit financially from Spectrum 10K?	2
What are the motivations and potential influence of funders?	3
Non-negotiable aspects of the study	2
What obligations does Spectrum 10K have to its funders?	1
Is Autism Speaks involved in Spectrum 10K?	1
Involvement	
How were autistic people involved in design and setup of Spectrum 10K?	1
Why were relatives and other stakeholders involved?	2
How can this better reflect diverse lived experience?	3
What is an appropriate level of community engagement for studies like Spectrum 10K in the future?	2
Approach	
Is it reasonable to explore autism in terms of a medical model (for example using diagnostic criteria) or should a social model be used?	3
How will the study recognise and celebrate positive aspects of autism?	3
Will the study seek to better understand lived experience of autism?	2

Question or concern	Anticipated depth
How will wider societal and environmental factors, including race, gender disparities and health inequalities, be taken into account during the study?	2
Topic: The Spectrum 10K research team	
General	
Who is involved in Spectrum 10K and in what capacity?	1
Getting to know those involved better	2
Motives	
What are the researchers' motives for conducting the research?	3
Are there any commercial aims and/or potential for diagnostic tests?	3
Values	
Do the researchers want to cure or prevent autism?	3
How are their past publications and comments connected to the current study? Do they contradict stated Spectrum 10K values and aims?	3
Topic: Aims of the study	
Benefit to autistic people	
Is this study going to benefit autistic people or improve wellbeing? If so, how?	3
What kind of timeline will these improvements follow?	1
How will expectations be managed?	1
How can the genetic aspects of Spectrum 10K benefit autistic people?	3
What are the advantages and disadvantages of identifying sub-groups of autistic people?	3
Do autistic people want medical treatments for any aspects of autism?	3
Will co-morbidities and co-occurring conditions be investigated as part of the study?	1
Do autistic people want medical treatments for co-occurring conditions?	2
Will the study have any wider benefits to support or education? (Balance between medical and social outcomes?)	3
Will the study have wider impact on education around autism (e.g. in schools, healthcare settings)?	2
Why isn't the funding being used for things like support and services?	3
Prenatal testing	
Addressing links between aims to cure and prevent autism, eugenics and genetic research, both past and present.	4
How does this study build on or relate to other studies into the genetics of autism?	2
Is a prenatal test (before birth) for autism possible, either now or in the future?	4
Even though Spectrum 10K is not looking for a prenatal test, could its findings lead to a prenatal test in the future?	4
Could a prenatal test for autism lead to pregnancies being terminated if the baby is autistic, as happens with Down syndrome?	2

Question or concern	Anticipated depth
Safeguarding against preventative outcomes (e.g. prenatal testing)	4
Stated aims	
What exactly are the study aims?	1
Why aren't the aims on the website exactly the same as stated in the grant?	2
Study processes	
Ethics	
Understanding original ethics approval	2
What were the specific problems with Spectrum 10K in the first place?	3
Use of DNA	
Why does Spectrum 10K need DNA?	1
What exactly will Spectrum 10K do with genetic data?	2
Will DNA be screened for other traits?	1
DNA sampling of family members and their data	2
Other data	
Why does Spectrum 10K need questionnaires?	2
How will medical records (Electronic Health Care Records) be accessed and used	2
Why does Spectrum 10K need access to medical records?	1
How will the study account for possible inaccuracy in medical records?	3
Is sharing medical records compulsory?	1
Data security	
How will Spectrum 10K data be stored and how secure will this be?	2
Including samples taken prior to study's pause	1
How will participant information and DNA samples be kept confidential and anonymous?	2
What will happen to Spectrum 10K data and samples after the project is finished?	1
Data access	
What data will be shared, why and how?	3
Who will have access?	3
Will participants have access to their own data?	2
What does it mean that Spectrum 10K is a 're-contactable resource'?	3
How will decisions be made about who can access Spectrum 10K data?	4
Data Committee Steering Group	3
Will autistic people have a say on who gets access to the data?	4
Will Spectrum 10K sell data?	1

Question or concern	Anticipated depth
Timeline	
When will the study restart?	1
How long will it take to complete?	1
Consent	
General	
Can DNA be removed from the study once it has been included?	1
What happens to Spectrum 10K samples and data if somebody withdraws from the study?	2
Will consent be transferred to external stakeholders accessing data?	2
Ensuring that the website and study documentation (such as Participant Information Sheets, Consent Forms and Easy Read documentation) are sufficiently clear.	3
Children	
What is the consent procedure for including children in Spectrum 10K (including withdrawal and re-consent)?	2
What is meant by 'assent'?	1
What will happen to DNA once a child becomes an adult?	2
Is it ethical to use DNA from children based on consent from their parents/carers, given that this cannot be retracted if the child decides later that they do not consent?	3
Adults without capacity to consent	
Why is it important to include adults without capacity to consent to participate?	1
How does Spectrum 10K include adults without capacity to consent to participate?	1
Is it ethical to use DNA from adults who lack the capacity to consent to participate, given that this cannot be retracted if the person is ever able to review the decision for themselves?	3
What methods will be used to demonstrate informed consent?	1