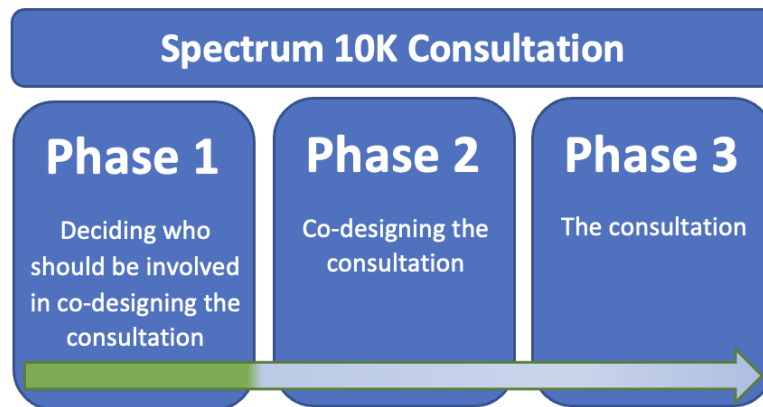


Spectrum 10K Consultation Update

Since our last update we have been working hard on the [consultation](#), which aims to improve the Spectrum 10K study. We can now provide information about the completion of Phase 1 and outline our plans for Phases 2 and 3.



A note on terminology

We use identity-first language ('autistic person' rather than 'person with autism') because we understand that this is the preference of the majority of (but not all) autistic people. When we refer to the 'autism community' we mean anybody who is autistic and those who are part of the wider community, such as those who support autistic people, such as parents/carers and autism professionals.

Within some models of community engagement and empowerment, 'consultation' is sometimes criticised as being tokenistic. We are committed to meaningful, non-tokenistic community engagement. This includes co-design of the consultation, with as much community involvement as possible, including appointing an autistic co-lead for the consultation. The goal is to improve Spectrum 10K by incorporating as many suggestions from the autism community as possible.

Introducing Hopkins Van Mil

The Spectrum 10K consultation seeks to hear and understand the views of people who are concerned with, or affected by, the issues raised by Spectrum 10K. It is a community engagement programme rather than a research project. As such, we have appointed [Hopkins Van Mil](#) to coordinate and facilitate the consultation. They are a small, independent agency specialising in participatory engagement programmes of this type, in areas such as health, social care, wellbeing, hardship, communities, environment and climate change. Their team of expert facilitators collaborates with communities to create a safe, inclusive, purposeful and stimulating environment to explore different perspectives and find constructive ways forward.

Phase 1: Deciding who should be involved in co-design

Phase 1 was carried out between December 2021 and February 2022. Its purpose was to seek opinions about who should be involved in Phase 2, the co-design of the consultation. Eight

virtual meetings were held via Zoom, each facilitated by Hopkins Van Mil and including between one and six participants. In total, 29 people engaged in Phase 1, plus the Spectrum 10K team.

One important aspect that emerged from the discussions was the importance of anonymity for consultation participants across all phases. We will therefore not give details that could identify those who took part. However, 23 were autistic and 6 were non-autistic parents/carers, clinicians or charity representatives. Some participants were already known to the team, while others were recruited independently, for example via peopleinresearch.org. We included a mixture of people who were supportive of the study and those who were critical. Some autistic researchers were included, as were some clinicians and charity representatives.

Hopkins Van Mil was asked to organise, host, and facilitate the meetings. Each conversation was focused on identifying who should be involved in Phase 2 and how that phase should work.

Phase 1: Outcomes

Hopkins Van Mil provided the Spectrum 10K team with a report on Phase 1, which Phase 1 participants had reviewed and commented on. The report can be found [here](#). Key points include the following:

Respect

- The co-design should not be tokenistic – those involved must be able to make a difference.
- Transparency and clear communication are vital (avoiding expert language and jargon, providing explanations where necessary).
- Phase 2 should truly be co-design.
- Facilitation should be independent.
- Autistic people should be the majority voice and should lead/facilitate.
- Trust and confidentiality are crucial. Anonymous participation must be an option.
- Participants should be reimbursed for their time and experience.
- We should look after the wellbeing of those involved, anticipate distress, and support people to contribute safely.
- We should use respectful language when talking about autism (for example not using words that are inherently pathologising or deficit-based).

The process

- Those involved should agree to participate to improve the study, not stop it.
- There should be clear meeting agreements, plus aims and objectives for each of the phases.
- The difference between Phase 2 (co-design) and Phase 3 (consultation) must be clear.
- The co-design process should be created around clearly defined questions and themes.
- The co-designed plan should allow inclusion of concerns that have not yet been identified.

Accessibility and inclusivity

- We should be inclusive, allowing as many people as possible to take part if they want to.

- We need accessible approaches (for example workshops, polls during workshops, the chat function during workshops, surveys, email responses to specific questions and use of Augmentative and Alternative Communication (AAC) methods where appropriate).
- We should allow processing/ thinking time.
- We should allow participation outside of standard office hours.

Who should be involved?

We have used the suggestions provided in Phase 1 to create a list of stakeholder groups (i.e., all those who have an interest in the study). We will not make a hierarchy within this list, other than to ensure that autistic people are the majority voice. We will include as many people as possible, to allow maximum representation across the autism community. It is likely that the same stakeholder groups (though not necessarily the same people) will need to be included across both Phases 2 and 3, so that those groups can contribute to both the co-design of the consultation, and the consultation itself. However, we expect larger numbers of each group to be included in Phase 3.

Where possible, in each stakeholder group we will include a mix of those who are supportive and those who are critical of the study. We will also aim to include, for example, a range of ages, ethnicities, genders, and those who are LGBTQ+.

We will invite participants from the following stakeholder groups to both Phases 2 and 3:

Autistic people, including:

- Those who can independently communicate verbally (aged 16 and over)
- Non-speaking autistic people and their advocates
- Autistic people who use Augmentative and Alternative Communication (AAC)
- Autistic people with learning disabilities
- Autistic people with co-occurring conditions and/ or who have multiple disabilities

Parents and carers, including:

- Autistic and non-autistic parents/guardians of autistic children
- Autistic and non-autistic parents/guardians of non-speaking autistic children
- Autistic and non-autistic parents/guardians of autistic children with learning disabilities
- Autistic and non-autistic parents/guardians of autistic children with co-occurring conditions and/ or who have multiple disabilities
- Parents/carers of autistic people who lack capacity to consent to participate in Spectrum 10K

Others, including:

- The Spectrum 10K research team
- Autistic people conducting academic research (into autism or other topics)
- The existing Spectrum 10K advisory panel
- The Spectrum 10K ambassadors (though see the update on ambassadors, below)
- Specialists in participatory design and research
- Charities representing autistic people and their families

- Clinicians and/or health and social care professionals who work with autistic people and their families
- Researchers from other autism studies
- Representatives from bioethics organisations

Phase 2: Co-designing the consultation

(expected June 2022)

Having reflected on all the suggestions from Phase 1, we will take the following approach to Phase 2:

1. Autistic leadership

We are seeking an autistic person/people with the required skills and experience to co-lead Phases 2 and 3 of the consultation, alongside the Spectrum 10K team and Hopkins Van Mil.

We are proposing a co-leadership arrangement because the Spectrum 10K team has ultimate responsibility to the Wellcome Trust and the University of Cambridge for delivering both the consultation and the project and therefore cannot step away from a leadership role. In order to provide an independent perspective, expertise in participatory engagement programmes, as well as administrative and organisational support, we propose that the existing third-party organisation (Hopkins Van Mil) **also act as a co-lead**.

More details about the co-lead roles and information about how to apply to be the autistic co-lead can be found [here](#).

2. Including as many people as possible

It is important that lots of people are included, from many different stakeholder groups (interested people). We have created a short survey to allow you to register your interest in either Phase 2 and/or Phase 3.

Please [CLICK HERE](#) to complete the survey. We will not collect information about you without your permission. IP addresses will not be collected.

3. The list of questions and concerns to be discussed

We have gathered a list of questions and concerns about Spectrum 10K from emails and comments online and via social media. Once people have been identified to take part in Phase 2, we will share this list with them, along with our up-to-date responses. The Phase 2 group will have an opportunity to add to the list of questions and concerns and will then decide on a plan to address all of them in Phase 3. Exactly how this will be achieved will be determined by the Phase 2 group and the co-leads.

Phase 3: The consultation itself

(expected August/September 2022)

Once a plan for Phase 3 has been finalised, we will share more information via our website.

Spectrum 10K Ambassadors

While we are very grateful to our Ambassadors for the support they have provided, we have decided to end this role. The reason for this is that it will be impossible to keep Ambassadors up to date as the consultation progresses, because things can change very quickly. This risks placing Ambassadors in a situation where they are asked questions that they cannot answer, simply because we have not had time to bring them up to date. We want to avoid any risk of public confusion about the project, and focus entirely on the consultation.

Finally, we, the Spectrum 10K team, would like to thank the members of the autism community who have helped with Phase 1 of the consultation.