

Call for expressions of interest: **Spectrum 10K Consultation Autistic Co-Lead**

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Background

Spectrum 10K is a research project 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 project launch in August 2021, thousands of autistic people 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 and the University of Cambridge, to allow time for large-scale and more diverse engagement with the autism community. The two years of engagement carried out before the project launch included a small number of autistic people, parents, and clinicians. The new consultation, which is running for approximately one further year, will include hundreds of autistic people, parents, clinicians, and other interested people (stakeholders), and will ensure a range of voices from the autism community are heard, with diversity across gender, ethnicity, intellectual disability, language level, co-occurring conditions, sexual orientation, age, and socioeconomic status.

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

The process has been divided into three phases:

- Phase 1: Deciding who should be involved in co-designing the consultation (Dec. 2021-Feb. 2022)
- Phase 2: Co-designing the consultation (expected July 2022)
- Phase 3: The consultation itself (expected September/October 2022)



Why are we looking for an autistic co-lead?

Phase 1 of the consultation took place between December 2021 and February 2022. Full details can be found [here](#). The process included talking with 23 people in small groups, as well as the Spectrum 10K team, about who should be involved in the co-design of the consultation. One key suggestion that emerged from Phase 1 was that an autistic person should lead Phases 2 and 3. A co-leadership arrangement is proposed, 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. Hopkins Van Mil is also proposed as a third co-lead, to bring first-hand insights from Phase 1, provide support in how to involve and work with people, and bring extensive experience in consultation administration, facilitation, analysis and reporting.

We recognise that this proposal is not the same as an autistic person leading the entire process alone, but it is the closest to this that can realistically be achieved for this project.

The co-leadership roles are explained in more detail below. In brief, the autistic co-lead(s), Hopkins Van Mil and Spectrum 10K team will all work together on decision-making about Phases 2 and 3. The autistic co-lead(s) and Hopkins Van Mil will manage the details of inviting people, arranging and facilitating meetings and other activities, with Hopkins Van Mil providing experience of participatory engagement and administrative support. Hopkins Van Mil and the autistic co-lead(s) will have responsibility for creating and reviewing transcripts of activities in Phases 2 and 3, and creating summaries. These will be presented to and discussed with the Spectrum 10K team, and the Spectrum 10K team will then use those summaries to make decisions about changes to the Spectrum 10K project.

How will the consultation proceed?

Phase 2: Co-designing the consultation (expected July 2022)

Based on discussions held in Phase 1, Phase 2 will involve groups of autistic people and other stakeholders who will review all the questions and concerns raised about Spectrum 10K and decide how each one should be addressed in Phase 3.

At the end of Phase 2, we expect to have:

- A finalised **list of questions and concerns** to be addressed in Phase 3
- A way of determining that each question or concern has been adequately addressed.
- An **outline of meetings/activities needed** to address the questions.
- An **outline of people needed for each meeting/activity**, and the expected mix of people from different groups (such as those with learning disabilities, users of Augmentative and Alternative Communication methods (AAC), different genders and ages, etc.)

Phase 3: The consultation itself

(expected September/October 2022)

Based on the Phase 2 outcomes, the autistic co-lead(s) and Hopkins Van Mil will arrange and conduct the meetings and activities required, and then work in partnership to analyse and summarise the outcomes.

Overview of co-leadership for Phases 2 and 3

(✓) = Optional

	Autistic person/ people	Hopkins Van Mil	Spectrum 10K
Play a key role in discussions and decision-making to plan and implement Phases 2 and 3.	✓	✓	✓
Invite and liaise with participants for Phases 2 and 3 and arrange meetings and activities.	(✓)	✓	
Facilitate/lead meetings and activities, ensuring all voices are heard.	(✓)	✓	
Produce quick, overview summaries and transcripts.	✓	✓	
Review transcripts of meetings and activities and create summaries using both qualitative and quantitative methodologies.	(✓)	✓	
Provide administrative and organisational support for interacting with many consultation participants, arranging meetings and other activities.		✓	
Provide funding for consultation.			✓
Take part in Phase 2 and 3 activities as a stakeholder group.			✓

The autistic co-leadership role will be made as meaningful as possible in the following ways:

- All discussions about the consultation will involve all three co-leads.
- While the autistic co-lead(s) will be funded by Spectrum 10K, there is no expectation that they should agree with all of the suggestions of the Spectrum 10K team or Hopkins Van Mil.
- Before commencing, all co-leads will agree how we will record (and make public) the process and outcomes of Phases 2 and 3, including where disagreements have occurred between co-leads and how they were resolved.
- Co-leads will be expected to discuss all issues until a conclusion can be reached that is acceptable to all of them. If an issue cannot be resolved, the Spectrum 10K team (as the party with ultimate responsibility for delivering both the consultation and the project) will make final decisions, and all co-leads will be open and honest about discussions held, any remaining points of disagreement, and the proposed action(s) to be taken.

The autistic co-lead role

Duties

We want to be as open as possible to find an autistic person or people to co-lead the consultation. For this reason, we are not yet specifying the exact terms of how this would be achieved, and it remains open for discussion. The exact duties and payment rate could be negotiated based on an individual's skills and experience, and we will provide support and accommodations/ adaptations as required.

While the details are open to discussion, we expect the role to include:

- Regular meetings with Hopkins Van Mil and the Spectrum 10K team to make decisions about the consultation.
- Working with Hopkins Van Mil to organise engagement activities such as online meetings.
- Facilitating online meetings (or co-facilitating) to ensure all voices are heard, including in meetings where there is strong disagreement.
- Working with Hopkins Van Mil to produce summaries of the meetings.
- Liaising with consultation participants to answer questions, arrange meetings, etc.

Key responsibilities for the Autistic Co-Lead(s)

1. Attend and contribute to regular meetings (online) with the Spectrum 10K team and Hopkins Van Mil in which the day-to-day management of the consultation is discussed and decisions are made.
2. Collaborate with Hopkins Van Mil to develop and implement a plan for recruitment of Phase 2 and 3 participants.
3. Communicate sensitively and maintain a high level of professionalism and diplomacy with members of all stakeholder groups, to explore whether they might participate in the consultation, explain the process, and answer questions.
4. Build rapport and good working relationships with consultation participants and potential participants.
5. Work with Hopkins Van Mil to coordinate and manage Phase 2 of the consultation so that the participants can create a detailed plan for Phase 3.

6. Work with Hopkins Van Mil to coordinate and manage Phase 3 of the consultation.
7. Act as an impartial facilitator for some consultation meetings and activities (others to be facilitated by Hopkins Van Mil or both Hopkins Van Mil and the autistic co-lead) (optional).
8. In partnership with Hopkins Van Mil, analyse and interpret information gathered during consultation, reflecting on feedback from different perspectives.
9. Summarise findings in partnership with Hopkins Van Mil.
10. Maintain confidentiality of participants and ongoing discussions during phase 2 and phase 3.
11. Work in line with data protection principles and GDPR (training & guidance can be provided).

Person specification

We are specifically seeking an autistic person because a key outcome of Phase 1 was that an autistic person should lead Phase 2 and Phase 3. We acknowledge that there are many people who self-identify as autistic, people who are waiting for an autism assessment, and people who have been unable to access such an assessment. We are also aware that this may disproportionately affect some groups within the autism community. We are therefore not actively specifying that applicants must be formally diagnosed as autistic, but we will ask at interview how they would respond if their autism were publicly brought into question.

If you're interested in this role, but don't meet all of the criteria, or would like to discuss this, please do contact us at consultation@hopkinsvanmil.co.uk to arrange an informal discussion.

We acknowledge that some of the communication requirements below are likely to be difficult for some autistic people. Therefore, we will work flexibly and adjust our ways of working, such as by allowing extra time for processing and preparation, creating short, written summaries in advance of meetings, and providing support with organisation and time management if required. Support will be available to meet candidates' needs for interview, and in the role.

General. You will:
Essential
<ol style="list-style-type: none"> 1) Be publicly involved with Spectrum 10K, as the role cannot be anonymous. 2) Be impartial in a role as facilitator - the role is not to express one's own views but rather to ensure all views are heard. 3) Have a minimum of 6 hours per week to dedicate to the project until end of November 2022. (This will need to be a mixture of weekdays, evenings and weekends). 4) Work on the basis that consultation is to improve, not stop, Spectrum 10K. 5) Respect other views, including other autistic people, parents and carers, researchers, clinicians, those who work in the medical model of autism, those who work in the social model of autism/disability. 6) Understand the requirement for confidentiality.
Desirable
<ol style="list-style-type: none"> 7) Have not publicly expressed strong views either for or against Spectrum 10K, as this would not be seen as impartial.

Previous experience. You will have:

Essential

8) Previous experience of managing challenging situations or conflicting demands.

Desirable

9) Experience in a relevant working environment (research, charity, clinical, social work, etc.,).

10) A university degree or equivalent level of practical experience/knowledge.

11) An understanding of the research process e.g., grant applications, study design, recruitment, ethics, measures, data analysis, data sharing, ethics and governance.

12) Previous experience of participatory processes: This includes involving people in research so that they can collaborate meaningfully on the findings and the outcomes. Such experience might include co-designing workshops, interviews or community platforms with research participants, co-designing methods of qualitative research to ensure research participants know they have power and influence in the process.

13) Facilitation experience: Key skills include supporting groups to do their best working, which includes listening as well as speaking; giving clear instructions; keeping the session to time; working flexibly to enable the group to follow unexpected lines of enquiry; supporting people to share their views in ways which are appropriate for them; ensuring contributions are heard from both dominant and non-dominant voices; managing conversations to ensure they keep their focus; being a trusted resource to support group discussions.

Working with autistic people. You will:

Essential

14) Have the ability to understand and be sensitive in managing the issues around autism and disability.

15) Have the ability to work positively when differences in social communication style occur.

16) Have the ability to communicate well with people from a range of backgrounds, with different communication styles and ability (with adaptations where necessary).

Personal characteristics/ skills. You will:

Essential

17) Have coping strategies for dealing with online criticism.

18) Have the ability to work well via video-conferencing, e.g., Zoom.

19) Have the ability to listen to and work with the views and needs of multiple stakeholders.

20) Have the ability to be professional and diplomatic in all settings, including social media. Please note that we will ask applicants to share their public social media details as part of the application process, so that these can be reviewed.

21) Have the ability to set aside one's own opinion in order to ensure others are heard, even when other people's views are not compatible with your own.

Desirable

22) Have excellent organisational skills, including time management and prioritisation. (We can support this if necessary).

Note: the role-holder will be required to obtain a Disclosure and Barring Service (DBS) check.

Practical details of the autistic co-lead role

Payment

The position will be a freelance contract between the role-holder and Hopkins Van Mil, paid within the range of £50 - £70 per hour, negotiable based on skills and experience. Please note that as a freelance contractor, the role-holder will be responsible for ensuring they pay the appropriate tax and National Insurance on this income.

Working Hours

We will guarantee a minimum of 6 hours per week, and expect that more hours will sometimes be available. Flexibility in working times will be required. For example, some activities will need to be conducted outside of office hours, and therefore the person must be available for some evening and weekend working. The exact days and times to be worked will be negotiable to be as flexible as possible whilst meeting the needs of the consultation.

Support for the autistic co-lead

Discussion about Spectrum 10K has revealed divided views, particularly online. Regrettably, some social media comments have also been offensive or abusive, particularly on Twitter. As the autistic co-lead role cannot be anonymous, there are concerns that they could receive in-session or online criticism or verbal abuse. These issues must be considered carefully. Hopkins Van Mil will offer support options. The person or people taking on this role will need to demonstrate an ability to be resilient in similar situations.

How to apply

If you are interested in this role, please email consultation@hopkinsvanmil.co.uk. You will need to:

- Complete a brief application form which can be downloaded [here](#)
- Send a CV
- Send a cover letter explaining why you are interested and how you meet the criteria for the role, above.

Please note that writing ability is not key to this role, so we will not assess CVs and cover letters on writing style or writing ability. Applications will be reviewed based on content and how well they match the person specification. However, we are open to alternative application formats for those who need them. If you would like to use an alternative format, such as a video or audio application, please email consultation@hopkinsvanmil.co.uk as soon as possible, to discuss.

The deadline for applications will be midnight at the end of Sunday 12th June.

We welcome applications from across the whole autism community and are committed to the values of equality, diversity, inclusion, dignity, respect and acceptance and to the neurodiversity model. We encourage members of minority groups to apply for this role.

We are open to two autistic people approaching us about this role if they have experience of working together. In these situations, both applicants should send a full application, as above, and provide the name of the person they propose working with.

Selection procedure

The expressions of interest will be reviewed by a selection panel including Hopkins Van Mil and the Spectrum 10K team, as well as some autistic people. Once the membership of this panel has been finalised, we will publish details (without personally identifiable information).

Progression to the next stage will be based on whether each application demonstrates a likely good fit with the person specification, including availability over the period of the consultation. We will notify all applicants about whether they have progressed to the interview stage by Thursday 16th June.

We will then hold meetings/interviews with those who have progressed to this stage, most likely via Zoom. These will allow us to ask questions about the information in the applications, and to continue to determine the best person or people for the role. We will publish the outcome, taking care to balance the individuals' rights to privacy with the need to be as transparent as possible about how the decision was made.

Contact us

If you have any questions, please email consultation@hopkinsvanmil.co.uk.