



This is what Spectrum 10K has said about:

Potential benefits to autistic people

1. Is this study going to benefit autistic people or improve wellbeing? If so, how?

There are no direct benefits of taking part in the study. However, Spectrum 10K will help to further our understanding of the relationship between genes, environment, autism and related conditions.

Spectrum 10K will help scientists better understand how genetic and environmental factors affect the wellbeing of autistic individuals, including their physical and mental health. In the longer term, after Spectrum 10K has ended, we hope this increased understanding will lead to improvements in the quality of support and care for autistic people and their families. This will require further research studies after Spectrum 10K has completed, and that work will not necessarily be completed by the researchers involved in Spectrum 10K.

The knowledge gained from Spectrum 10K will help promote greater understanding into the causes of the wide range of outcomes in autistic people including their strengths and talents. Findings from Spectrum 10K may inform future studies to identify who might benefit from different kinds of interventions, if they are seeking them.

2. How will the study recognise and celebrate positive aspects of autism?

Spectrum 10K aims to collect data about mental and physical health outcomes. Working within the neurodiversity paradigm, we emphasise that autism is characterised by differences, including strengths and talents. Examples that we study include measures of excellent attention to detail and memory for detail, and excellent pattern recognition.

We do also recognise that many autistic people understand autism to be a disability, so we also include questions about language development, social understanding, and learning disability in our questionnaires.

The language we use emphasises differences in both the mind and biology, rather than now outdated language referring to disorders or pathology, that could stigmatise. We hope that the language we use both when communicating with participants and when sharing research with scientific audiences will avoid stigmatising views of autism and instead celebrate the positive aspects of autism as one example of neurodiversity.



3. Why isn't the funding being used for things like support and services?

This study is funded by the Wellcome Trust. The Wellcome Trust is a charitable organisation that funds research into human health.

We support research into services and support for autistic people. While the Wellcome Trust funding cannot be used for these purposes, other bodies provide funding for this kind of research. We hope that funding for support and services will be increased in the future as we recognise that support services are inadequate and under-funded. This is true in both the NHS and Social Services. We are playing our part in trying to bring in more funding for support services through our charity, the Autism Centre of Excellence (ACE) at Cambridge.

4. Will the study have any wider benefits to support or education? (Balance between medical and social outcomes?)

Spectrum 10K is focused on health outcomes. It is unlikely that Spectrum 10K will directly benefit social support or education.

5. How will wider societal and environmental factors, including race, gender disparities and health inequalities, be taken into account during the study?

Whilst we cannot capture all of wider societal and environmental factors, we have endeavoured to capture some of these important factors using self-report questionnaires. For example, we ask people about any stigma and discrimination they have faced in one optional questionnaire. We also collect information about gender, ethnicity, educational attainment and income, to incorporate these into our analyses.

6. Will the study seek to better understand lived experience of autism?

Spectrum 10K is a quantitative research study because of its scale, and the questionnaires we use aim to capture autistic people's lived experience across a range of areas, as much as is possible within the limits of this type of research.