

Welcome to the Autism Spectrum Cohort Newsletter!

We are sending this newsletter to all organisations working with us to recruit adults on the autism spectrum, and relatives of adults. We aim to use the newsletter to let you know about our progress with recruitment, and some of the findings from our research to date. We hope you will find it useful!

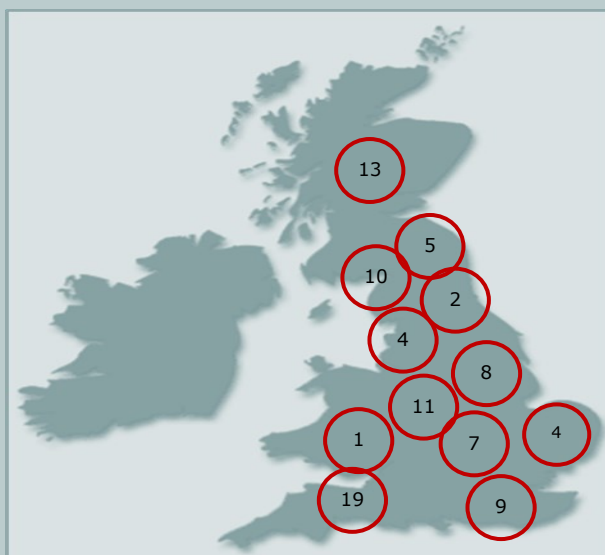
The Adult Autism Spectrum Cohort—UK (ASC-UK) is the national research cohort of and for adults on the autism spectrum and relatives of adults on the autism spectrum across the UK. The study is the first of its kind and collects information on topics such as health, education, support and employment. We hope that this might lead to improvements in services offered to the autism community. Participants are informed at regular intervals about the progress of the study. Adults on the autism spectrum are working with the researchers as part of the research team.

Trusts and Organisations working with us

26 NHS Trusts and 67 voluntary organisations joined us in 2015 to recruit adults on the autism spectrum and relatives of adults. We are pleased to be working with so many groups! Thank you for your efforts!

The map shows the number of NHS Trusts and voluntary organisations currently working with us in different regions across the UK. We plan to increase the number of sites and organisations across the UK over the coming months. A list of NHS Trusts and organisations working with us can be found on our website:

<http://research.ncl.ac.uk/adultautismspectrum>



Progress with recruitment and plans for 2016

More than **300 adults** and over **70 relatives/carers** joined the cohort in 2015.

During 2016, we want to increase participation and aim to reach our target of being in touch with **500 adults on the autism spectrum and 500 relatives/carers**. Thank you for continuing to let adults, and relatives of adults know about the study! People can sign up online or complete paper forms.

- We are including adults on the autism spectrum of all ages and abilities
- Relatives or carers can respond for people with an autism spectrum condition who cannot take part themselves
- Relatives can also join and give information about themselves and their own lives

In 2016 we will be inviting some people who are part of the cohort to discuss with us in detail aspects and periods of their lives which have gone well, and those that they would like to have gone better. We would like to have these more detailed discussions as it is not always possible to fully understand what issues are important to people from questionnaires alone.

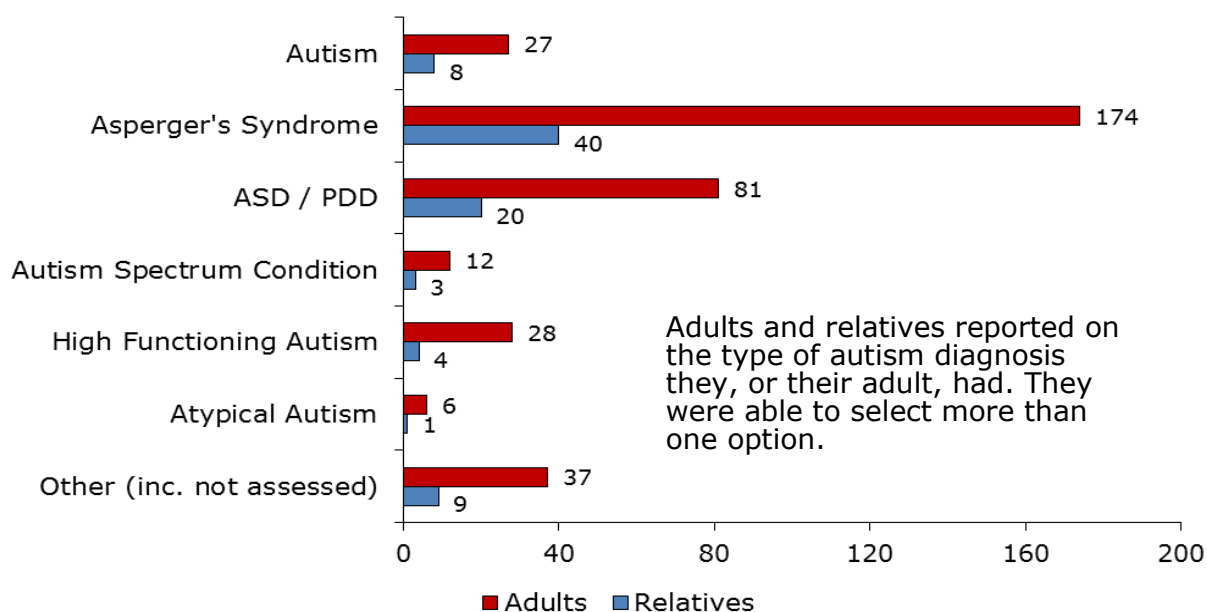
Some initial information about the people joining ASC-UK

308 adults on the autism spectrum

- 154 males, 123 females, 8 adults who reported 'other gender'
- Average age = 41 years (range 18 to 86 years)
- 62% registered online and 38% completed paper forms
- 23 had information completed by a relative or carer as they lack capacity to complete the questionnaire themselves

72 relatives of adults on the autism spectrum

- 12 males and 60 females
- Average age = 56 years (range 23 to 81 years)
- 56% registered online and 44% completed paper forms



The ASC-UK team



Back row, from left

Richard Hardy (IT and database support)
Prof Ann Le Couteur (Co-Lead)
Jane Tilbrook (Administrator)
Debbie Wilde (Programme Administrator)
Dr Jeremy Parr (Lead for ASC-UK)

Front row, from left

Deborah Garland (Autism Resource Centre Manager in NE)
Joan Mackintosh (Research Associate)
Dr Alex Petrou (Research Associate)

Prof Helen McConachie (Co-Lead, not present)
Dr Tom Berney (Researcher, not present)

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Adult Autism Spectrum Cohort-UK



@uk_asc #ascuk