

As World Autism Day approaches on 2nd April and a week of increased awareness around autism begins, we are very excited to share with you an update of our study - The Adult Autism Spectrum Cohort—UK (ASC-UK). This is a national research cohort including adults on the autism spectrum, and relatives of adults on the spectrum. It 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 study's findings. Adults on the autism spectrum and relatives are working as part of the research team.

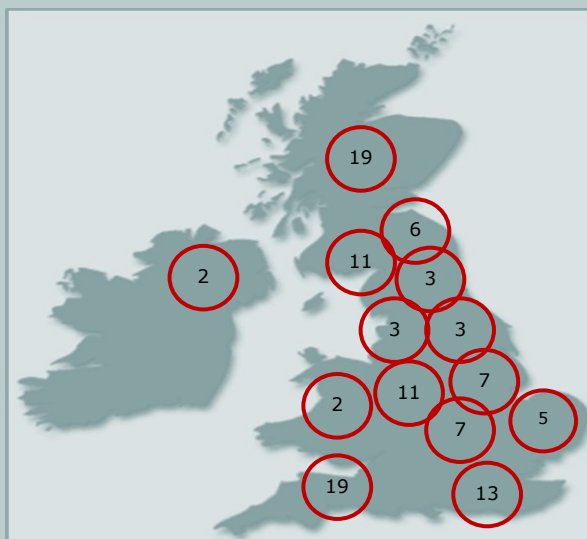
Trusts and Organisations working with us

22 NHS Trusts and **89 voluntary organisations** are now working with us to recruit adults on the autism spectrum, and relatives of adults. This number is increasing all the time. 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. The number of sites and organisations across the UK will continue to increase 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>

If your organisation would like to work with us, please contact adultautismspectrum@ncl.ac.uk or **0191 282 1380 / 5965 / 5966**



Progress with recruitment and plans for 2016

By March 2016, around **400 adults** and **110 relatives/carers** have given consent to join the cohorts.

During 2016, we want to increase participation and aim to reach our initial target of being in touch with at least **500 adults on the autism spectrum** and **500 relatives/carers**.

People can sign up directly online or by completing paper forms, see

<http://research.ncl.ac.uk/adultautismspectrum>. We are recruiting 3 groups:

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

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

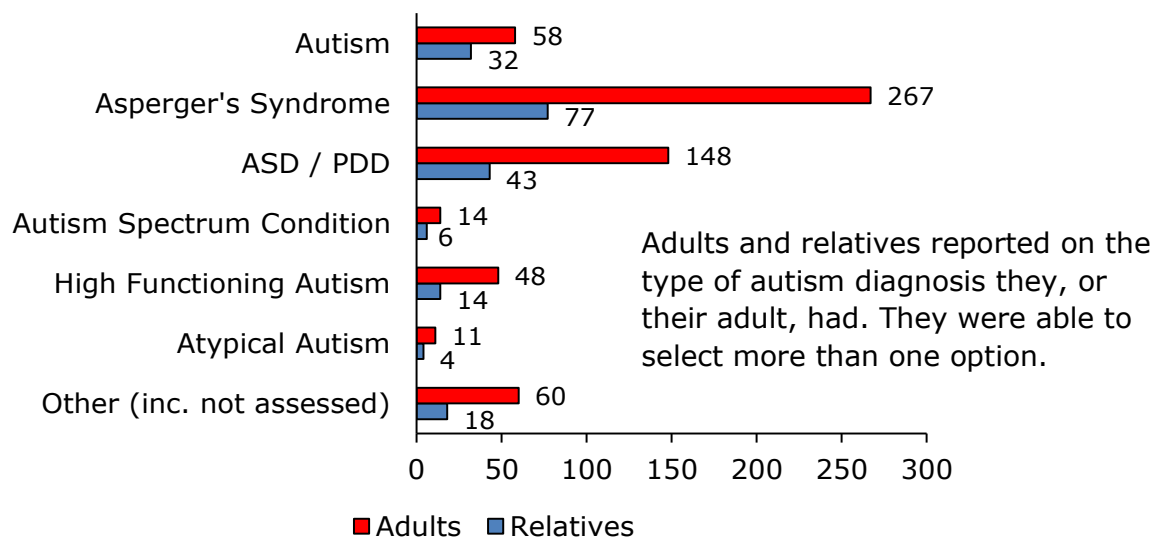
Some initial information about the people joining ASC-UK

494 adults on the autism spectrum have contacted us about taking part

- 285 males, 198 females, 11 adults who reported 'other gender'
- Age 18-24 (20%), 25-34 (24%), 35-44 (18%), 45-54 (20%), 55-64 (11%), and 66-86 (5%). No date of birth given to calculate age (2%)
- 53% registered online and 47% completed paper forms
- **403** adults have now consented to take part in this research
- **73%** have now completed the first questionnaire

162 relatives of adults on the autism spectrum have contacted us about taking part

- 24 males and 138 females
- Age 18-24 (3%), 25-34 (1%), 35-44 (9%), 45-54 (37%), 55-64 (31%), and 66-74 (11%). No date of birth given to calculate age (8%)
- 39% registered online and 61% completed paper forms
- **110** relatives have now consented to take part in this research
- **60%** have now completed the first questionnaire



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)

Not present

Prof Helen McConachie (Co-Lead)
Dr Tom Berney (Researcher)
Cos Michael, Chis Mitchell and The Goth (Autistic researchers)

Contact ASC-UK

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Adult Autism Spectrum Cohort-UK



@uk_asc #ascuk