

Welcome to the Autism Spectrum Cohort Newsletter!

This newsletter is for adults on the autism spectrum, and relatives of adults who are involved in the study, as well as for all NHS Trusts and organisations supporting the research. We aim to use the newsletter to let you know about our progress with recruitment, and keep you up to date with some of the findings.

The Adult Autism Spectrum Cohort—UK (ASC-UK) is a 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 and relatives are working as part of the research team.

A big thank you to everyone who is supporting this research

What do people think about the research?

Many people have made comments and suggestions about ASC-UK and we welcome all feedback:

"It is good that I have an opportunity to express my experiences"

(Autistic adult)

"It is good to be able to write freely, and not just tick boxes as sometimes information does not fit neatly into boxes"

(Relative of an autistic adult)

**"The questions are simple and straightforward making them easy to answer
Also, plenty of multiple choice options"**

(Relative of an autistic adult)

THE WORLD HEALTH ORGANIZATION QUALITY OF LIFE (WHOQOL) QUESTIONNAIRE

'Quality of life' in autistic adults

Adults who join ASC-UK fill in the World Health Organisation Quality of Life questionnaire (WHOQoL) but autistic adults have told us the questionnaire misses out some important issues. The ASC-UK study team has now been successful in getting additional research funding so we can explore further 'Quality of Life' for autistic adults. To start this study, some adults who live in the North East are being invited to take part in discussions to tell us their views. Then we expect to create some new questions to add to the WHOQoL. We hope the autistic participants in the cohort will be interested in completing the revised questionnaire later in the year. Helen McConachie and David Mason are leading this research (david.mason@newcastle.ac.uk).

Some information about the people joining ASC-UK

By May 2016, **558 adults** and **176 relatives/carers** have given consent to join the cohorts

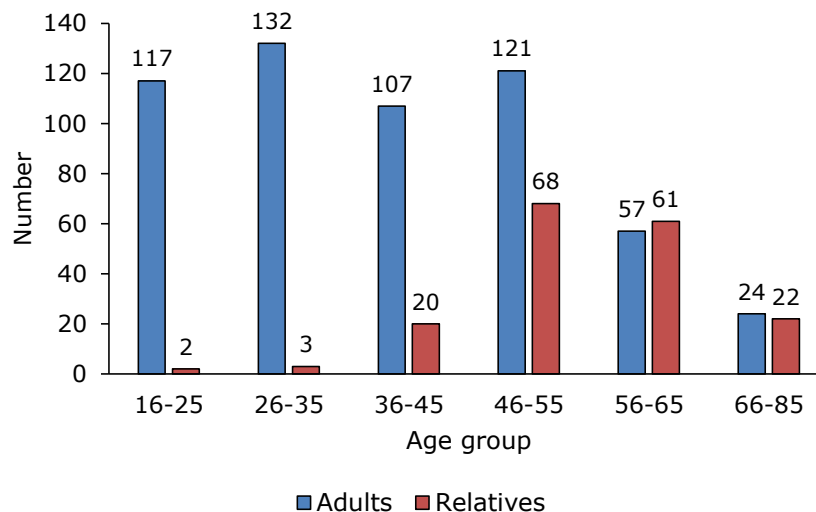
Adults on the autism spectrum

- 308 males, 237 females, 13 adults reported 'other gender' or did not want to report it
- 61% registered online and 39% completed paper forms
- 39 adults (7%) lacked the capacity to consent for themselves

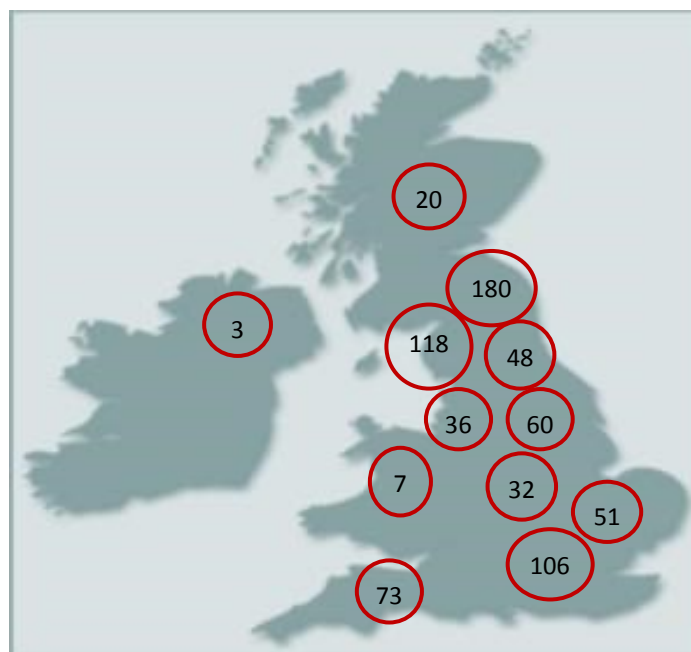
Relatives of adults on the autism spectrum

- 23 males, 152 females, 1 relative did not want to report their gender
- 56% registered online and 44% completed paper forms

The chart shows the number of adults and relatives consented to ASC-UK in the different age groups. We are very pleased to have adults from across the age range joining.



This map shows the number of adults and relatives consented to ASC-UK in different regions of the UK by May 2016.



Presenting some early findings: Autism Europe 2016 conference

In September 2016, we will be presenting some of the early findings from ASC-UK and associated projects at the Autism Europe conference in Edinburgh

Initial analysis of our data shows that:

- Mental health conditions are common in autistic adults
- Autistic adults who are in employment report fewer mental health conditions
- There is a significant gender difference in quality of life with males having a significantly higher quality of life than females

We will also have a stand at the Autism Europe conference—hope to see some of you there!
<http://www.autism.org.uk/autismeurope>

How do people hear about ASC-UK?

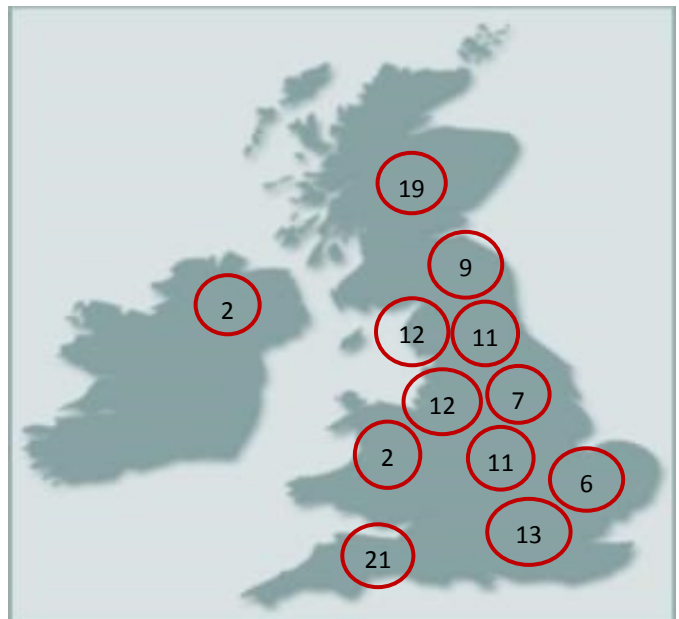
Many adults, and relatives, are now hearing about ASC-UK through their local NHS organisation, but lots of people hear about the research through other sources



Trusts and Organisations working with us

35 NHS Trusts and **90 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!

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 and 2017

During 2016 and 2017, we continue to recruit both autistic adults and relatives of autistic adults. **Do you know anyone who might be interested in taking part?**
If you do, please let them know about this research.

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 on the autism spectrum who cannot take part themselves
- Relatives give information about themselves and their own lives

In May 2016, the Royal College of General Practitioners invited 8000 GP practices to support recruitment to ASC-UK. We very much hope that this will lead to more organisations letting adults and relatives know about the study. We have started to invite 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. Jeremy Parr and Joan Mackintosh are leading this research (joan.mackintosh@newcastle.ac.uk).

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 & The Goth (autistic researchers)

Contact ASC-UK

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Adult Autism Spectrum Cohort-UK



@uk_asc #ascuk

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