

Welcome to the Autism Spectrum Cohort Newsletter!

This newsletter is for adults on the autism spectrum, and relatives/carers who are involved in the Autism Spectrum Cohort-UK (ASC-UK), as well as for all NHS Trusts and organisations supporting the research. We use the newsletter to let you know about our progress with recruitment, and keep you up to date with research findings.

2018 has been a busy year for us so far! More than **2450 adults on the autism spectrum, and relatives/carers of adults**, have joined the cohorts. We have started to analyse data, publish and disseminate some findings relevant to people's everyday lives, as well as starting new research. Progress with recruitment is shown below. We have included summaries of research findings, and links to research papers on page 2 and in the insert.

Some information about the people joining ASC-UK

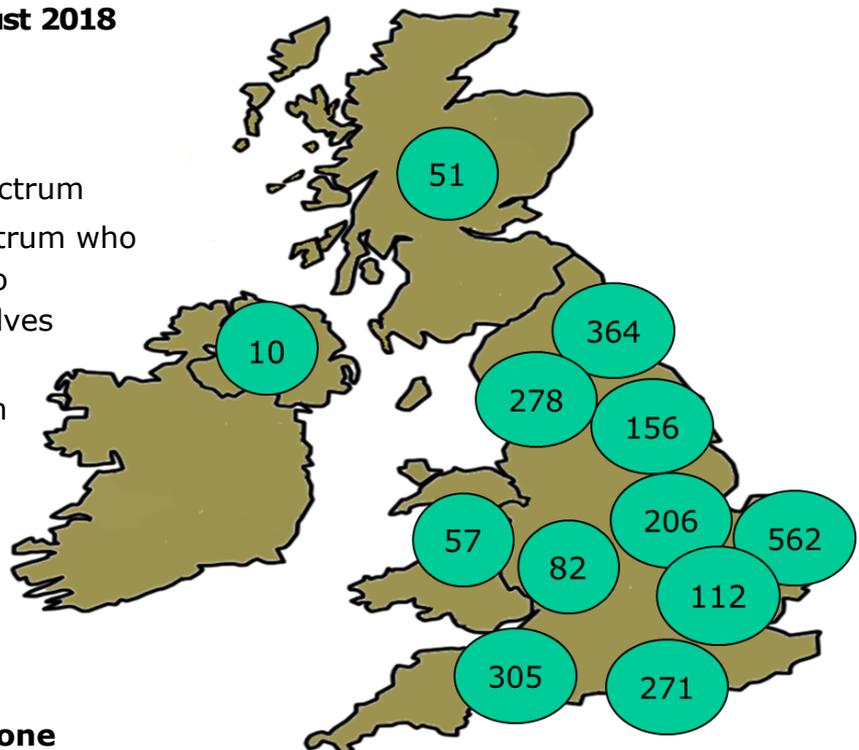
This research is allowing us to learn about the lives of adults on the autism spectrum and relatives/carers of adults. The map shows from where in the UK people on the autism spectrum and relatives/carers have joined by August 2018.

2454 people had joined **by August 2018**

This includes:

- 1604 adults on the autism spectrum
- 128 adults on the autism spectrum who lack the capacity to consent to research participation themselves
- 722 relatives/carers of adults on the autism spectrum

53% registered online and
47% completed paper forms



**Thank you to everyone
who has joined!**

Current and forthcoming studies related to ASC-UK

National Anxiety Survey and Personalised Anxiety Treatment for Adults on the Autism Spectrum

We recently started a two-year study which aims to help us better understand and treat anxiety in adults on the autism spectrum. This study is called Personalised Anxiety Treatment-Autism (PAT-A). Recruitment has begun on a large national survey; gathering the views of people on the autism spectrum, relatives/carers and healthcare professionals about the experiences of anxiety for adults on the autism spectrum across the lifespan. This includes learning about their experiences of available anxiety treatments. Everyone who let us know previously that they have experienced anxiety is being contacted.

We have had an excellent response! We are still recruiting to the survey and we hope to hear the views of as many people as possible. Using this information, we will make clinicians and policymakers aware of the difficulties anxiety causes, people's views about NHS services, and what needs to change to improve anxiety treatment. We will also use information to create a personalised intervention approach that we hope will be more 'fit for purpose' for adults on the autism spectrum. Finally, we will test the feasibility, acceptability and efficacy of this treatment in a pilot randomised control trial.

**For more information, please contact:
Dr Sam Brice, Anxiety.Autism@newcastle.ac.uk**

Improving the Health of Older Autistic People

A two year research study called Improving the Health of Older Autistic People (IHOAP) started in September 2017. We have completed focus group discussions with adults on the autism spectrum, people who support adults on the autism spectrum, and health professionals. We have also reviewed the research about people's healthcare needs. Later in 2018, we will undertake the first large scale survey about physical health and healthcare.

This information will be used to inform professionals and policymakers about how services need to change to improve healthcare access for adults on the autism spectrum. The information will also be used to help inform the development of a novel approach to facilitating access to healthcare that we will then pilot with people aged 50+ who live around Newcastle. We hope the results of this study will lead to facilitating access to health-related services for people on the autism spectrum.

**For more information, please contact
Mr David Mason, David.Mason@newcastle.ac.uk**

Results from our research

We have included two inserts that set out some results from our research: One relating to Quality of Life research and the other about adult diagnosis research. In future newsletters, we will include summaries of research findings. You might also be interested in reading our published research papers from 2018. Some of these can be found at:
<https://research.ncl.ac.uk/adultautismspectrum/publications/>

Response to a previous newsletter

Stacy Reed shared her experiences with us and readers appreciated this personal account. Matthew Price would also like to share his experiences (with permission):

"I, very much like 'Stacy', have been diagnosed with autism and Aspergers. I was diagnosed with this along with ADHD when I was 10. Let me tell you about me. My name is Matt and I am 27 years old, and have been living on the spectrum now for 17 years. It's interesting to look back on it, as those 17 years have flown by. Where have they gone? Again, just like Stacy, I have no learning difficulties. At school, I was always ahead of the game so to speak. Academically, I took 3 GCSEs a year early. I was 15 and passed them with A grades. I too like routine, and am very reluctant to change. I find it difficult to adjust. It baffles my head! What is weird with me is that I don't particularly enjoy new places, but I thrive when I'm meeting and talking to new people. I too like Stacy, find it hard to keep friendships. I always find that I'm quite cynical when it comes to a friendship. I find myself asking the questions "What do they want?" and "Why have they chosen to be friends with me?" I too like Stacy think that I have a good memory and am particularly good at numbers and spelling. I'm very good with words and often find solace in writing. I'm an avid writer and am currently writing a biographical piece, which I'm thoroughly enjoying."

Trusts and Organisations working with us

We now have a large number of NHS Trusts, Primary Care providers (GPs), and voluntary organisations working with us to recruit adults on the autism spectrum, and relatives/ carers of adults. This includes:

- **100 Voluntary organisations**
- **55 NHS Trusts**
- **75 Primary Care providers**

A list of NHS providers including Primary Care, and organisations working with us can be found on our website:

**[https://research.ncl.ac.uk/adultautismspectrum/
trustsandorganisationsworkingwithus/](https://research.ncl.ac.uk/adultautismspectrum/trustsandorganisationsworkingwithus/)**

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



Events

We held our second event for professionals who are supporting recruitment to ASC-UK on 13th and 14th March 2018 at Newcastle University. Feedback was excellent:

"An excellent example of a research study feeding back and communicating with the people who feed into the recruitment around the UK. Thank you."

"All presentations and discussions were informative and thought provoking."

We plan to hold two more Newcastle University events in 2018:

- **Discover Lecture, 14th November 2018.** Please check Autistica's Discover Network website for further details.
- **Professionals Adult Diagnosis Workshop, 27th November 2018**

Do you know anyone who might be interested in taking part? If you do, please let them know about this research

ASC-UK is the national research cohort of and for adults on the autism spectrum, and relatives/carers of adults 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 people on the autism spectrum. 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.

People can sign up directly online or by completing paper forms, see <http://research.ncl.ac.uk/adultautismspectrum/>

We are recruiting 3 groups of people:

- Adults on the autism spectrum of all ages and abilities (confirmed diagnosis not required)
- Relatives or carers who can respond for people on the autism spectrum who cannot take part themselves
- Relatives or carers give information about themselves and their own lives

The ASC-UK team



Back row, from left

Deborah Garland

(National Autistic Society Autism Resource Centre Manager in NE)

Carla Black (Programme Administrator)

Prof Jeremy Parr (Lead for ASC-UK)

Front row, from left

Dr Alex Petrou (Research Associate)

Richard Hardy (IT and database support)

Prof Ann Le Couteur (Co-Investigator)

Not present

Dr Tom Berney (Researcher), Dr Marc Woodbury-Smith (Co-Investigator)

Jahnese Hamilton (Clinical Studies Officer)

Cos Michael, Chris Mitchell, The Goth & Colin Wilson (Autistic Consultants)

Contact ASC-UK

 0191 282 1380 / 5965 / 5966

 adultautismspectrum@ncl.ac.uk

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



Institute of Neuroscience
Henry Wellcome Building
Newcastle University
Framlington Place
Newcastle upon Tyne
NE2 4HH



Adult Autism Spectrum Cohort-UK



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