

Welcome to the Autism Spectrum Cohort Newsletter!

This newsletter is for adults on the autism spectrum, and relatives/carers of adults on the autism spectrum 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 some of the findings.

A big thank you to everyone who is continuing to support this research as well as professionals and participants new to the cohorts!

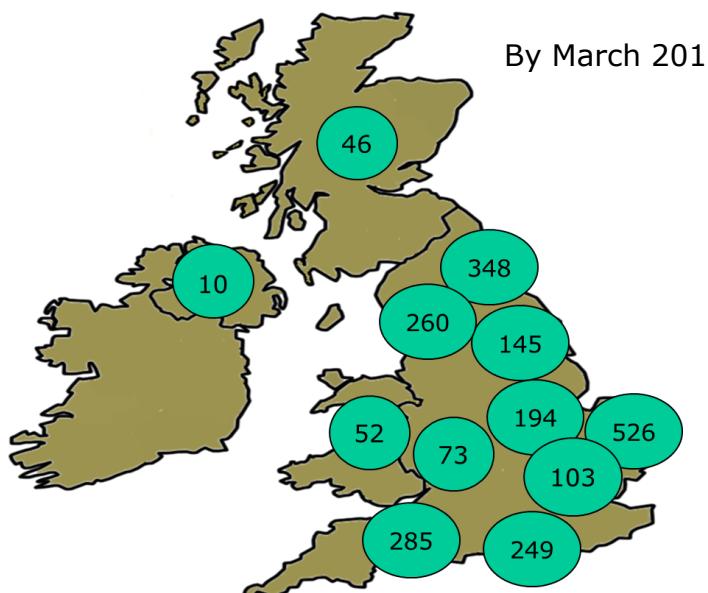
We are very pleased to celebrate two pieces of exciting news with you.

- First, we have been so successful and achieved well over our original recruitment targets of 500 autistic adults and 500 relatives/carers. By **March 2018**, **1611 autistic adults** and **680 relatives/carers** had given consent to join the cohorts. This is an increase of over 600 autistic adults and over 300 relatives/carers since our Spring 2017 newsletter. Our new targets are 2000 autistic adults and 750 relatives/carers.
- Second, Autistica who fund ASC-UK will carry on supporting the cohorts throughout 2018. We are still recruiting until at least September 2019.

Some information about the people joining ASC-UK

This research is allowing us to learn about the lives of autistic adults and relatives/carers of autistic adults.

This map shows from where in the UK autistic adults and relatives/carers of autistic adults have joined.



Adults on the autism spectrum

- 856 males, 713 females, and 42 people reported 'other gender' or did not want to report their gender
- 124 people (8%) lacked the capacity to consent to research participation themselves but took part with help from a relative/carer
- 58% registered online and 42% completed paper forms

Relatives/carers of adults on the autism spectrum

- 100 males, 577 females, and 3 relatives/carers did not want to report their gender
- 41% registered online and 59% completed paper forms

Forthcoming studies related to ASC-UK

Getting an autism spectrum diagnosis in adulthood, and support or services received afterwards

This study is in the final phase and is due to be completed in December 2018. The aim of the study is to create evidence to support ways of improving diagnostic pathways for adults suspected of having Autism Spectrum Disorder (ASD). We are doing this by researching the methods used for the diagnosis of ASD in adults in the UK National Health Service (NHS) by (1) surveying people who have received a diagnosis of ASD as an adult and their relatives about their experience of the diagnostic process and (2) surveying UK professionals who diagnose ASD in adults about current NHS service provision. The surveys started in March 2018 and we are currently collecting and preparing to analyse data received. As part of the study we have also developed and are now piloting a new interview for use during the process of diagnosing ASD later in life in adults when little or no early developmental history is available. Finally the study has also involved a review of research evidence published on the use of ASD diagnostic tools with adults since the NICE guideline (National Institute for Health and Care Excellence [Clinical Guideline 142]). This work is now published and can be accessed via the following links:

<https://doi.org/10.1177/1362361317748245> and <https://eprint.ncl.ac.uk/243274>

(Newcastle University open access manuscript version). We hope the findings from this study will provide NHS policymakers and professionals with evidence based information about efficient and effective ASD diagnostic pathways for adults, and also about the types of support that people diagnosed during adulthood and their relatives wish to receive.

For more information, please contact

Dr Sarah Wigham, Sarah.Wigham@newcastle.ac.uk.

Personalised Anxiety Treatment for Autistic Adults

In September 2017 we started a two-year study which aims to help us better understand and treat anxiety in people on the autism spectrum. This study is called Personalised Anxiety Treatment for Autistic Adults (PAT-A). We will conduct a large national survey, gathering the views of autistic people, relatives/carers and professionals about the experiences of anxiety for individuals on the autism spectrum, including their experiences of treatments that are currently available. Using this information, we hope to adapt current NHS anxiety treatments to make them 'fit for purpose' for use with autistic adults, before testing their feasibility, acceptability and efficacy in a pilot randomised control trial. **For more information, please contact**

Dr Sam Brice, Samuel.Brice@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. This is an exploratory project, and we will begin by conducting surveys and focus groups discussions with the autistic adult community, their significant others and health professionals. This information will provide the basis to help inform the development of a novel approach to facilitating access to healthcare which we will then pilot with the older adult community with ASD. We hope the results of this study will lead to facilitating access to health-related services for autistic adults.

For more information, please contact

Mr David Mason, David.Mason@newcastle.ac.uk.

Response to our Spring 2017 newsletter

In our Spring 2017 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):

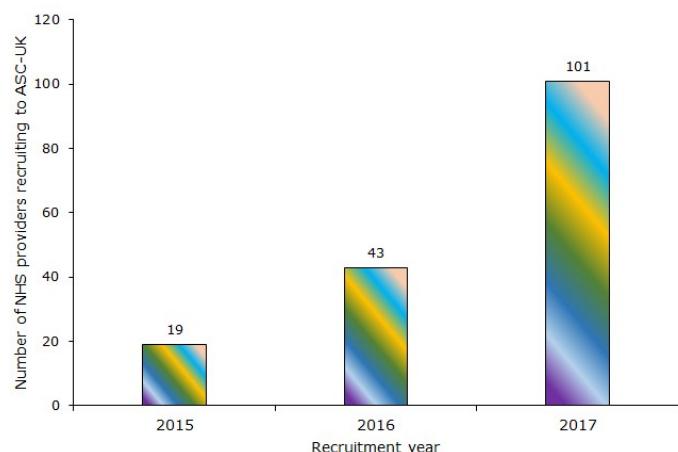
"I, very much like 'Stacy', have been diagnosed with autism and Aspergers. I was diagnosed with this along with ADHD when I was 10. Let me tell you about me. My name is Matt and I am 27 years old, and have been living on the spectrum now for 17 years. It's interesting to look back on it, as those 17 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

Since recruitment started in 2015, we now have over **100 voluntary organisations** working with us to recruit autistic adults, and relatives/carers of autistic adults.

This graph shows the number of **NHS providers including primary care** recruiting to ASC-UK over time.

The number of sites and organisations across the UK will continue to increase over the coming months.



We are pleased to be working with so many groups!

A list of NHS providers including primary care, 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**

Continuing Professional Development event

We are pleased to have held our **second CPD event** for professionals who are supporting recruitment to ASC-UK. This took place on **13th and 14th March 2018** at **Newcastle University**. Feedback from delegates was excellent. We hope to run the meeting again next year. Watch out for dates!

"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."

What is ASC-UK and who is it for?

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

Progress with recruitment

During 2018, we will continue to recruit both autistic adults and relatives/carers 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 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

Jahnese Hamilton (Clinical Studies Officer)
Dr Tom Berney (Researcher)
Deborah Garland (National Autistic Society Autism Resource Centre Manager in NE)
Dr Alex Petrou (Research Associate)
Dr Jeremy Parr (Lead for ASC-UK)
Prof Helen McConachie (Co-Lead)

Front row, from left

Dr Faye Wolstenhulme (Programme Administrator)
Richard Hardy (IT and database support)
Prof Ann Le Couteur (Co-Lead)

Not present

Cos Michael, Chris Mitchell, The Goth & Colin Wilson (Autistic researchers)
Joan Mackintosh (Research Associate)

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  @uk_asc #ascuk