# Adult Autism Spectrum Cohort-UK
# Winter Newsletter 2020

## 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.

We hope that you and your family are managing to stay safe and well. We could not write this newsletter without mentioning the difficult months we have all faced. We have included some helpful resources and links for you at the end of the newsletter together with an update on some research we shared with you in previous newsletters.

Like many of you, we adapted to the COVID-19 situation by working from home and have been visiting our Newcastle University office where social distancing allows We have been following government and University guidelines in order to ensure the safety and wellbeing of our staff. Throughout the lockdown and since, we have continued to answer e-mails and collect post from participants ensuring responses sent to us have been safely stored.

## Some information about the people who have joined 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 July 2020.

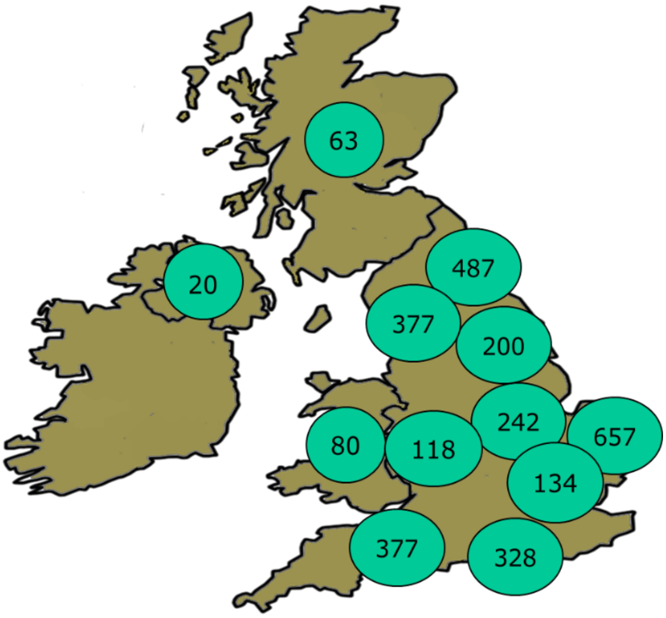
**3083** people had joined **by autumn 2020**

This includes:

- 2219 adults on the autism spectrum including 147 adults who lack the capacity to consent to research participation themselves
- 864 relatives/carers of adults on the autism spectrum

54% registered online and 46% completed paper forms

Thank you to everyone who has joined so far



# Trusts and Organisations working with us

We have a large number of NHS Trusts, Primary Care providers (GPs), and voluntary organisations working with us. This includes:

- **100 Voluntary organisations**
- **54 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/**

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# Reflections on lockdown

**Written By Colin Wilson**
**Autistic Advocate and Project Administrator**

One of the phrases I've seen regularly over the past few months is "I hope you are well in these unprecedented times". For most people the past few months have been a unique experience. For me, it's the first time I've really had to worry about getting food; felt uncomfortable in my own home rather than it being a safe retreat; and, for someone who has an interest in politics and public policy, it's the first time in my adult life I've had no idea what the rules are from one day to the next.

Whilst the nation was clearing the shelves of toilet rolls and pasta, I was on a daily hunt for specific foods so that I could continue to feed myself. It took several days searching for that rare can of baked beans that don't have vinegar in the ingredients (a big sensory issue for me) and coping with the anxiety of queuing for hours, and the changing and confusing pro- cesses where people seem to have less patience for someone to work it out was exhausting and everything else falls apart. Is it an essential journey? It's essential for me, but would anyone else understand that it can't just be any can of beans?

After many miles of walking day after day I had success but they only have single tins and a sign saying "4 per customer". I felt my heart sink. Trolleys surrounded me being filled with four large multipacks of the vinegar laced varieties. I found my words and approached a store assistant, explaining that I just wanted enough to last me a couple of weeks, I'd spent several days searching walking dozens of miles on foot. "Sorry but it's the policy now. Just get two of these, they work out cheaper anyway". I took a breath to explain further, but just didn't have the strength. "It's only a tin of beans", I reminded myself. But it isn't really. It's the realisation that my restricted diet and difficulty feeding myself when I’m overwhelmed or anxious was going to make the coming months even more difficult to navigate.

On reflection I don’t think it is that these ‘times’ are that unprecedented for autistic people. Whilst many of these challenges have been amplified, these are common experiences for many of us. I remember having to visit dozens of pharmacies across the region for a close relative. A change in supplier medication meant that the size and texture of the new tablets were difficult to tolerate. Blood sugar levels were spiking and anxiety was increasing each day. On our pharmacy visits, at each counter there was a long conversation explaining that we needed to know which brand they had in stock, only to be met with puzzled faces and explanations that they all work the same way.

It’s not about tins of beans. It’s not about a particular box of tablets. It is about the extra stress of finding understanding and coping with the uncertain situation that we are all in right now. We cope with these challenges on a regular basis. But during the pandemic many services have been unable to operate, schemes like autism friendly shopping were suspended, places of sanctuary like museums and community centres closed down, and health and social care services reached breaking point.

There have been positives in the last few months seeing communities pull together with online groups crafting face masks made from more sensory friendly materials for those that can tolerate wearing a face covering, or helping each other with navigating that difficult phone call. I was uplifted when I saw that a plea on an online autism group to replace a specific water bottle was met with offers to send matching replacements from around the country and even from abroad.

As we move on in the coming months, it is going to be important to keep autism on the agenda. As a community we often feel the impact of change fastest, and more severely; but it also feels like we can be the first to be forgotten. I’m very grateful to all of the participants who have supported ASC-UK and the associated projects, especially during these difficult times. Now, more than ever, we know how important the evidence is to improve mental health outcomes, reduce social isolation, and learn more about the lives of autistic people and their families.

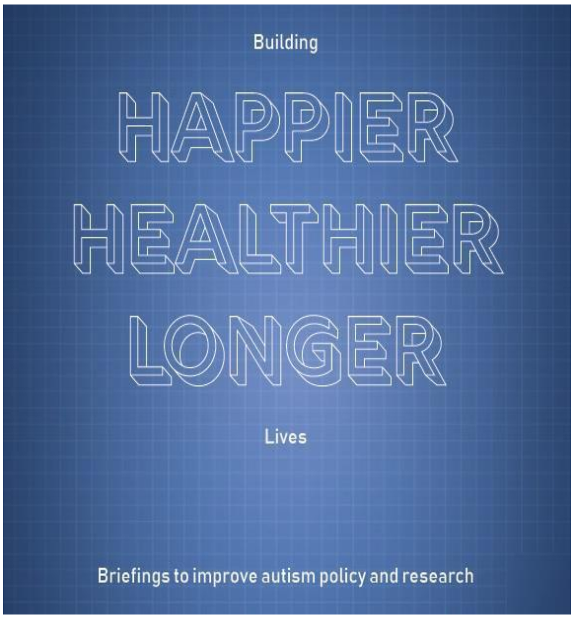
# Research Update

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

During this study we identified ways to improve diagnostic pathways for adults suspected of having an autism spectrum condition. We researched the methods currently used for diagnosing autism in adults in the UK National Health Service (NHS) by (1) surveying people who received a diagnosis of autism as an adult and their relatives about their experience of the diagnostic process, and (2) surveying UK professionals who diagnose autism in adults about current NHS service provision. We completed data collection in December 2018 - more than 340 autistic people took part. We used findings from the surveys to contribute to writing four inserts for a briefing document ('Building Happier, Healthier, Longer Lives' published in 2019 by the UK charity Autistica.

The purpose of the Briefings was to collate information to highlight issues of priority and current importance to autistic people and make recommendations to influence UK policy. Our research findings contributed to the following topics:

- *Access to adult diagnosis*
- *The adult diagnostic process*
- *Post-diagnostic support for adults*
- *Diagnosing autistic women and girls*



Autistica sent the documents to UK national government policy makers in June 2019.

If you would like to read the publication it can be accessed on the ASC-UK Cohort website or using the link here: https://www.autistica.org.uk/news/autism-strategy

Through the study, we made recommendations about how NHS diagnostic services should change. We are discussing these changes with the people who run the NHS, to see if they will put the changes into NHS practice.

## Autism Clinical Interview for Adults (ACIA) Project

During this part of the study we created and used a new interview called the Autism Clinical Interview for Adults (ACIA). Autistic people were positive about the new interview, and made important suggestions about the process and questions. The interview can be used by clinicians during the process of diagnosing autism in adults, when little or no information is available about childhood. If the person having the assessment agrees, the interview can also be used to get information about that person’s strengths and difficulties in adulthood from someone who knows the person well. This project was completed in December 2018, and we then published the findings in a journal article in 2020. If you would like to read the Newcastle University library version of the article it can be accessed using this link: https://doi.org/10.1089/aut.2019.0052

We also presented the study findings to more than 70 UK NHS professionals who diagnose autism in adults at a meeting in Newcastle in 2018. The clinicians were very interested in receiving training on how to use the new ACIA interview. We are now preparing online training materials for professionals who diagnose autism on how to use the new autism interview we developed during the study – we hope teams will start to use it in early 2021.

The ACIA measure has been discussed in a new report from the Royal College of Psychiatrists. All this means it is much more likely that the ACIA will be used in NHS clinical practice.

This study has contributed to building the research evidence base and to informing policy development regarding autism diagnostic services for adults and we are very grateful to everyone who took part.

***For more information about this study please contact: Dr Sarah Wigham, Sarah.Wigham@newcastle.ac.uk***

## National anxiety survey and Personalised Anxiety Treatment–Autism (PAT-A)

Anxiety is common for autistic people and often causes difficulties in everyday life, and has been highlighted as a research priority by the autism community. Therefore our research has focussed on further understanding autistic people's experiences of anxiety and improving treatments and services for autistic people.

### Anxiety Survey

More than 550 autistic adults completed our anxiety survey as well as relatives and parents of autistic children. Recruitment to the survey is now closed, however we have been analysing and sharing this important data in several ways, some examples of which are listed below:

We have developed a self-report anxiety questionnaire specifically for use with autistic adults. This tool is effective at recognising anxiety and key factors that may be particularly important to autistic people. This means that anxiety is less likely to be missed and more targeted treatments can be offered to autistic people. This questionnaire is freely available from our website.

We have identified key adjustments to make physical and mental healthcare services more acceptable and accessible to autistic people. These were in three themes: 1) Adjustments to the sensory environment (e.g. quieter waiting rooms), 2) adjustments to the clinician's knowledge and communication (e.g. clinician's understanding of autism) and 3) adjustments to the healthcare context (e.g. offering support prior to attending an appointment). Our research identified that these adjustments were seen as being very important to autistic people but rarely available to them. This identifies a gap in current healthcare provision that may mean that autistic people are less likely to receive the healthcare that they need. We have submitted this research to a scientific journal and have shared these findings with the people who run the NHS with the aim of reducing barriers to healthcare for autistic people.

### Personalised Anxiety Treatment – Autism trial (PAT-A)

We are still collecting data for our trial that looks at the feasibility and acceptability of delivering an NHS personalised psychological therapy to autistic adults who are anxious. This work is expected to be complete by the end of 2020 and we will share the findings in 2021. As part of this work, we have developed new ways of understanding and treating anxiety in autistic adults and we hope that this will inform more effective treatment options so that fewer autistic people live with anxiety.

***For more information about any of this work, please contact Dr Sam Brice***, ***Anxiety.Autism@ncl.ac.uk***

## Results from our Research

**Did you know that most of our research findings are freely available to read, for people who are taking part in the ASC-UK cohort projects?**

Some of these can be found at the following link:
https://research.ncl.ac.uk/adultautismspectrum/publications/

## Useful links to resources to support your mental health during coronavirus

https://www.autistica.org.uk/what-is-autism/coronavirus/tips-for-managing-mental-health-coronavirus

https://www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/

https://www.youtube.com/watch?v=iIpvdMVnfGs&feature=youtu.be

https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips/

https://www.anxietyuk.org.uk/blog/health-and-other-forms-of-anxiety-and-coronavirus/

The ASC-UK team would like to thank everyone for their support in 2020, and we send you best wishes for 2021! We look forward to sharing more news and research opportunities with you soon.

## Contact ASC-UK

If you would like to contact us, you can do that using email, or by writing to us:

Email: adultautismspectrum@ncl.ac.uk

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

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