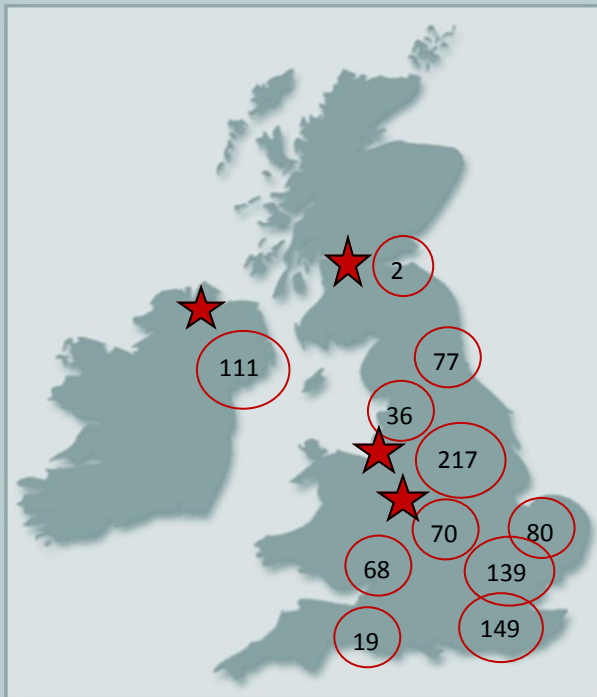


## The 1000th family joined ASD-UK in October!

Over 60 NHS child health teams have now joined ASD-UK and recruit families so they have an opportunity to take part in ASD research.

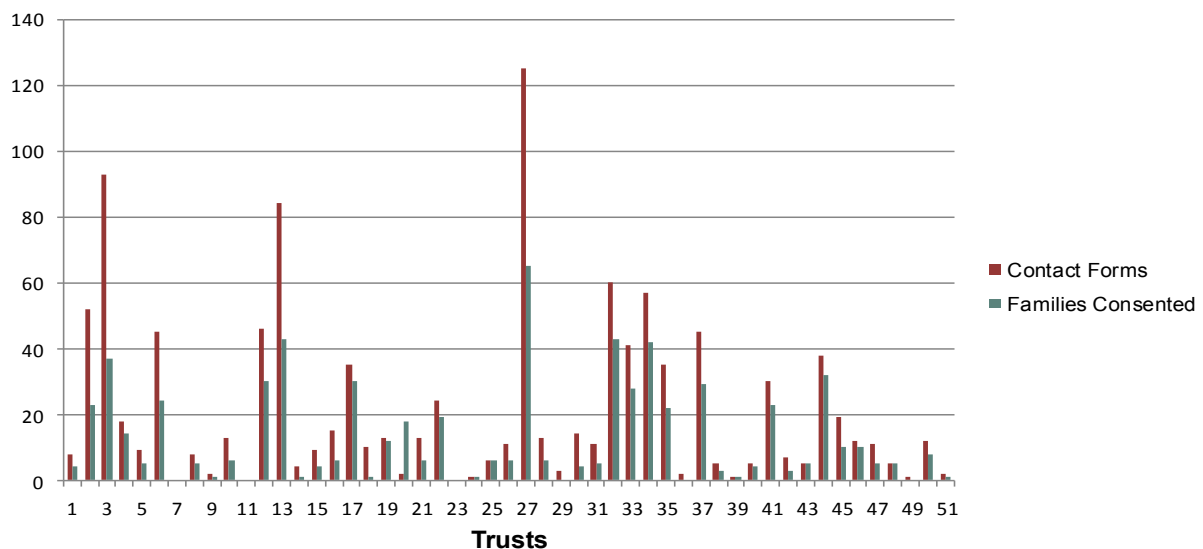
This map shows the number of families taking part from different regions. In addition, some families contact us directly about taking part. The red stars show new areas that will be recruiting families in 2014.



The chart below shows the spread of families recruited through clinics by participating Trusts. The red bars show the number of contact forms received from child health teams. The green bars show families who have completed the consent form and questionnaire and can be contacted about research projects.

Ten teams have now contacted families by letter from their lists/records of children with an ASD diagnosis. 380 families have joined ASD-UK through this route. **Please let us know if you have a list/record of children with an ASD diagnosis that you would like contact by letter about ASD-UK. We do most of the work involved in contacting families, and provide all letters and envelopes.**

Clinic recruitment and consents by child health teams



## Recruiting families for research from ASD-UK

We invite all UK ASD researchers to contact us about recruiting families from ASD-UK. If you know of researchers who want to recruit families please contact us or direct them to the ASD-UK website [www.asd-uk.com](http://www.asd-uk.com). Guidelines for recruiting families and an application form can be found there.

### Studies recruiting families from ASD-UK

**ASD+ - Dr Beena Koshy, Newcastle University.** ASD+ aims to identify the impact of behaviour problems on families of children with ASD, and families' experiences of the services available to support them. ASD-UK families have been contacted about ASD+ and almost 400 families are now taking part. A further 250 families are also taking part from the regional ASD database in North East England (Dasl<sup>n</sup>e). ASD+ is the biggest study so far in the UK about children with ASD and behavioural difficulties will help us understand more about these problems. **As Beena's project was on the NIHR Portfolio, your NHS Trust was awarded 'accrual' for each family from your Trust who participated. This means your Trust benefits from you recruiting families to ASD-UK!**

**Seeing the world differently — Dr Liz Pellicano, University of London.** This project is interested in the way that children with autism might see things differently from children who don't have autism.

**Repeating words and sentences — why do some children find it hard? - Hannah Hobson, University of Oxford.** This project is looking at whether some children do better if information is presented by a computer, rather than a person, and if children's ability to copy words is related to their ability to copy movement. It is also looking at whether an ability to repeat words and sentences relates to children's attention to different kinds of sounds.

**Autism and Technology – gathering parent wisdom on using technology with children with autism in the home - Dr Sue Fletcher-Watson, University of Edinburgh.** This study aims to find out more about how children with autism use technology in the home, alone or with their parents, and to use that information to begin to provide evidence-based guidelines for parents. The goal is to gather the views of experienced parents in order to then provide information to people who are less experienced with technology.

### Autistica Survey: One in a hundred — putting families at the heart of autism research. *Simon Wallace, Jeremy Parr and Alison Hardy*



Last year we told you about a survey conducted by Autistica to consult with parents of people with ASD about: **1.** what they think are important areas for autism research and **2.** how they would like to receive new information about ASD. Autistica will use the answers to help prioritise some of their future research funding. This included the views of parents and individuals from ASD-UK.

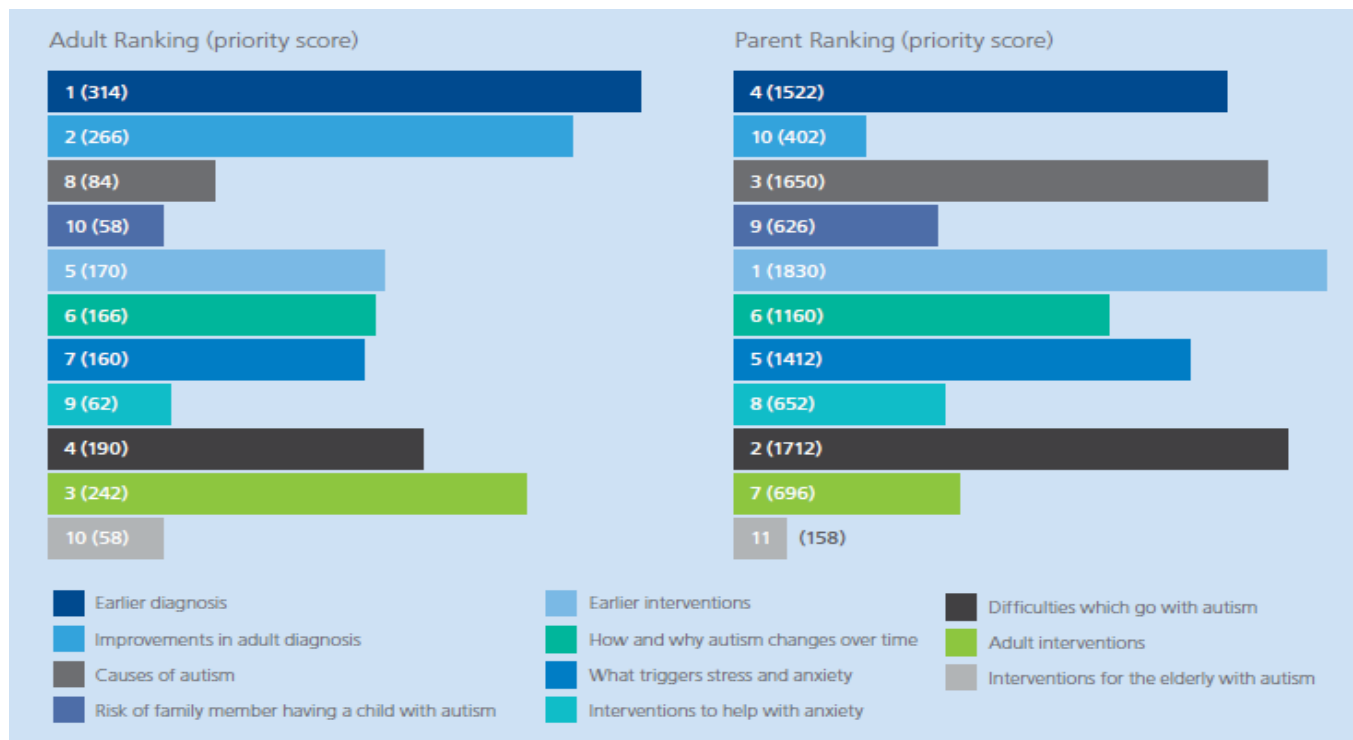
The 'One in a Hundred' report is the result of the survey with almost 1000 parents and individuals with autism. The survey included a large online questionnaire, telephone interviews and focus groups.

This consultation is a first step in an on-going process by Autistica to look at greater engagement with families and improve communication between families, researchers and medical practitioners in order to set research priorities.

## Autistica Survey: Putting families at the heart of autism research (cont.)

Information was collected in 4 key areas: Living with autism, Attitudes to scientific research, Experiences of the UK health system, Research priorities. The table below shows the research priorities for adults and parents.

The full report can be found at: [http://autistica.org.uk/document\\_downloads/Reports/Autistica-1-100-Report.PDF](http://autistica.org.uk/document_downloads/Reports/Autistica-1-100-Report.PDF)



### Other News

**Online Registration** Parents can now register online by visiting the ASD-UK website [www.asd-uk.com](http://www.asd-uk.com). They can complete the consent form and parent questionnaire. Parents will still send the SCQ and any medical and education reports by post in a pre-paid envelope.

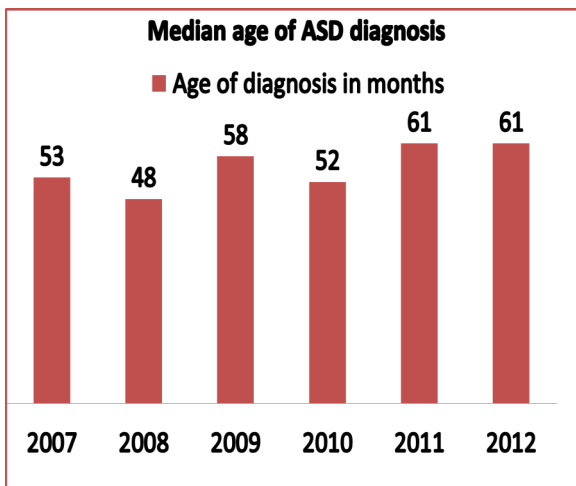
We would like to have more CAMHS teams participating in ASD-UK and we will be in touch with you about this soon. Please could you discuss ASD-UK with CAMHS colleagues? If you think they might be interested, please email them, and us.

### Visits to sites winter and spring 2014

- January 21st Durham and Darlington
- Jan 24th Alder Hey Children's Hospital
- February 5th SW Thames BACD
- February 19th North Thames network
- March 14th Belfast
- March 18th Greater Glasgow & Clyde
- April 24th Worcestershire Royal Hospital

If you have a regional meeting we can come and present on the progress of ASD-UK, please contact us (details over the page)

## Recent data gathered through ASD-UK



Data on the age at diagnosis were available from 735 children, 2 – 18 years (601 boys, 124 girls, male:female ratio of 5:1)

58.3% of children were diagnosed before age 60 months

20.5% of children were diagnosed aged under 36 months

The median age at ASD diagnosis remains around age 5 years. We are currently writing a paper that describes the age at diagnosis in more than 2500 families, and will tell you about this in the next newsletter.

## The ASD-UK team

**New staff** ASD-UK has grown over the last 18 months, with more teams helping to recruit families. We now have 2 additional days of researcher and administrative time. From 2014, Denise Brett will be sharing the day to day co-ordination of ASD-UK with Frances.



**Back row from left:** Sarah Nolan (administrative support), Richard Hardy (IT support), Jeremy Parr (ASD-UK lead), Helen McConachie (ASD-UK co-investigator), Frances Warnell (research associate and ASD-UK co-ordinator). **Front row, from left:** Anna Hodgson (research assistant) and Denise Brett (research assistant and co-ordinator from March 2014).

**And finally** thank you to all the teams that have contributed towards the success of ASD-UK for their support and we look forward to continued progress in 2014.

**Thank you everyone for working with us on ASD-UK!**

## How to contact us

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