Engaging in Autism Research: Summary of Findings

You might remember taking part in an online survey in spring or summer 2014? The survey was sent round to members of the autism community across Europe. We asked people for their opinions about a specific category of autism research: work with infants and toddlers, looking to identify the earliest signs of autism and then develop supports for that age group. This report provides a summary of what we found. The findings are now being written up for publication in an academic journal but will also be shared with researchers in the field at an international conference and via a special report.

Who took part? We were lucky enough to receive responses from 2381 people across eleven European countries. In the UK alone, 271 people took part. These included parents of children with autism, practitioners in health, education and social services, charitable sector employees and of course, autistic adults.

What did we find? Nearly everyone who took part in the survey strongly agreed that early autism research is important (see pie chart below), and that the most important areas of early autism research were understanding the genetic basis of autism and describing the earliest signs of the condition. Developing supports was also a key issue, but many participants (about 40%) were still interested in taking part in studies which didn’t offer an intervention component.

Want to know more? Please do get in touch directly if you have any questions or comments or if you’re interested in hearing more about our research:

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Participant Report, Dec 2014

The graph above shows what kind of language people prefer for talking about infants in early autism research: the most popular options are at the top of the graph.

Key statements

These are some of the statements about early autism research that people in our survey strongly supported:

• Sharing information between researchers and participating parents is essential
• Getting earlier diagnosis of autism is important
• Long-running studies should be responsive to families’ needs and opinions