

Autumn 2016



## PACT & PACT 7-11 Newsletter



# PACT 7-11 Findings Published!

**We are pleased to announce our findings from the PACT 7-11 Follow-Up Study. These are now published in The Lancet, a highly influential medical journal.**

You may remember that you took part in our follow-up study which ran between 2013 and 2015. We had a fantastic response from families. We were able to make contact with 95% of the original 152 PACT families and 88% (126) of those contacted agreed to take part. We would like to express our immense gratitude to you and your family for your continued involvement. Without your help, none of this important research would be possible.

### Children who received PACT therapy showed reduced autism severity

You may remember that we carried out the ADOS (Autism Diagnostic Observation Schedule) with your child, twice during PACT and once in the follow-up. This was watched and scored by a 'blinded' researcher, that is, someone who did not know anything about your child or whether or not you received additional therapy. This assessment gives us a measure of the severity of your child's autism. We found that those children involved in PACT therapy showed reduced scores on this assessment, compared to children who had continued without the therapy. These group differences were first noticeable at the end of the trial period, and were maintained at the follow-up 4-6 years later.



To understand this group difference, we calculated the percentage of children in each group who had autism of "high severity". At the end of the PACT trial 15.4% fewer children in the therapy group were classified as having autism of "high severity" (29% compared to 44% of children who continued without additional therapy) and during the follow-up it was 17.2% fewer children (46% compared to 63%).



Long-term improvements were seen in both social communication and in restricted and repetitive behaviours. These reductions in autism severity were also reported by parents in the questionnaires that you completed. The agreement between the observations from independent researchers and parents gave us confidence in these findings.

### Children who received PACT therapy initiated communication more with their parent

During PACT and the follow-up, we made videos of you and your child playing together as naturally as possible (not always that easy to do, we know!). One of our researchers watched the clips and essentially counted the number of times your child initiated communication with you (e.g. asked for something using words or non-verbal signals, pointed something out, or told you something). Children who had not received additional therapy showed a consistent pattern across time; around 26-27% of their communication was initiations. Children who received PACT therapy started to initiate a lot more when they were involved in the therapy. This did drop off over time but initiations remained about 30% of their communication at follow-up. This small but significant increase would make a difference to the sense of a two-way exchange that a parent experiences when interacting with their child at home. Also, importantly, we carried out an analysis that showed that the increase in the amount that the child initiates with their parent was linked to the improvement in their overall autism symptoms.



## PACT 7-11 Findings Continued

### PACT therapy did not affect the level of language development

As part of the follow-up study we carried out standardised language assessments with your child to find out what he/she can understand and say. There was huge variability in the language abilities of the children aged 7-11 years. Whether or not families had received PACT therapy did not affect the actual *level* of the child's language development, but it did improve the *use* of this language within social communication.

### High levels of child mental health difficulties were reported

We asked you to complete an online survey asking lots of questions about your child's emotional wellbeing. Your reports highlighted the extent of mental health needs in children with autism of this age. For example, around 36% of children showed significant behavioural / oppositional difficulties and around 29% showed high levels of anxiety / obsessive-compulsive features.



These findings are really important. They offer strong evidence to support what many of us believe: that early intervention for families with a young child with autism can bring about long lasting benefits. Empowering parents to develop their naturalistic interactions with their child may mean that these changes are then embedded within the everyday life of the child so that changes can be maintained beyond the end of the therapy programme. This study has also highlighted further work we autism researchers need to do! Language skills

are critical for daily functioning and we need to consider how we can better bring about improvements in this area. In addition, the extent of mental health and wellbeing difficulties reported in this age group is of huge concern and an important focus for us in the future.



We would like to express our thanks to you and your family for your committed contribution in the PACT project. Participation in randomised controlled trials like PACT does not necessarily bring about benefits to every individual taking part, but without the involvement of families like yours we could not rigorously evaluate new interventions to find out how they may benefit families in the future.

If you would like a copy of the paper or to discuss the findings in more depth, please do not hesitate to get in touch:

By email: [Kathy.leadbitter@manchester.ac.uk](mailto:Kathy.leadbitter@manchester.ac.uk)

or

By phone: 0161 275 5969

(Please leave a message if there's no answer and we'll call you back)

## In Other News

The PACT team is embarking on a new large and high-profile Randomised Controlled Trial called the Paediatric Autism Communication Trial—Generalised (PACT-G Trial).



As you probably know, many children with autism have difficulty generalising new skills from one context to another, and this represents a challenge in spreading the benefits of therapy into other aspects of everyday life. We have therefore developed the PACT therapy to include a greater emphasis on generalisation. We hope that, by delivering it to both a parent and a key person from the child's school or nursery, the child will communicate better in a range of contexts and with different people. We are also interested in the effectiveness of the therapy across a wider age range, involving children aged between 2 and 11. You can read more at: [www.pact-g.org](http://www.pact-g.org)

