

# Pre-school Autism Communication Trial Newsletter

## 50th Participant Randomised!!

In February of this year PACT randomised its 50th participant—we now have well over 70 families participating in the study. We are very grateful to all our referrers who are continuing to offer patients the opportunity to take part in this study. Recruitment is going well but we still need you to keep referring children who fulfil the inclusion criteria through this year up to January 2008. Any assistance that is required is available from the PACT trial office.

## Don't Forget the Inclusion and Exclusion Criteria to PACT

### *Inclusion Criteria*

- Child between 2 years and 4 years 9 months with presumptive or confirmed diagnosis of 'core' ICD 10 Autism
- Child has above 12 months equivalent level in general (non language) development
- The family have spoken English at home which is adequate to allow them to participate in this communication based intervention
- Neither child nor parent has long term severe hearing or visual impairment that would limit participation in the intervention
- No current clinically severe psychiatric illness in parents

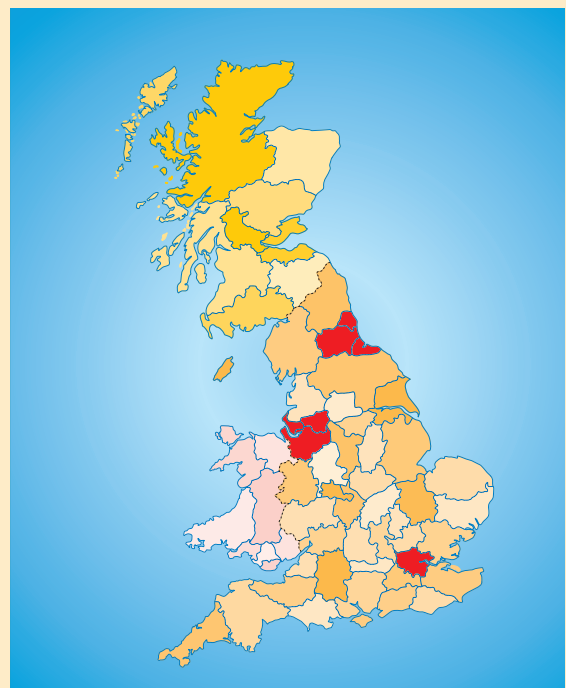
### *Exclusion Criteria*

- Epilepsy requiring regular medication
- Twins

## First Trial of its Kind

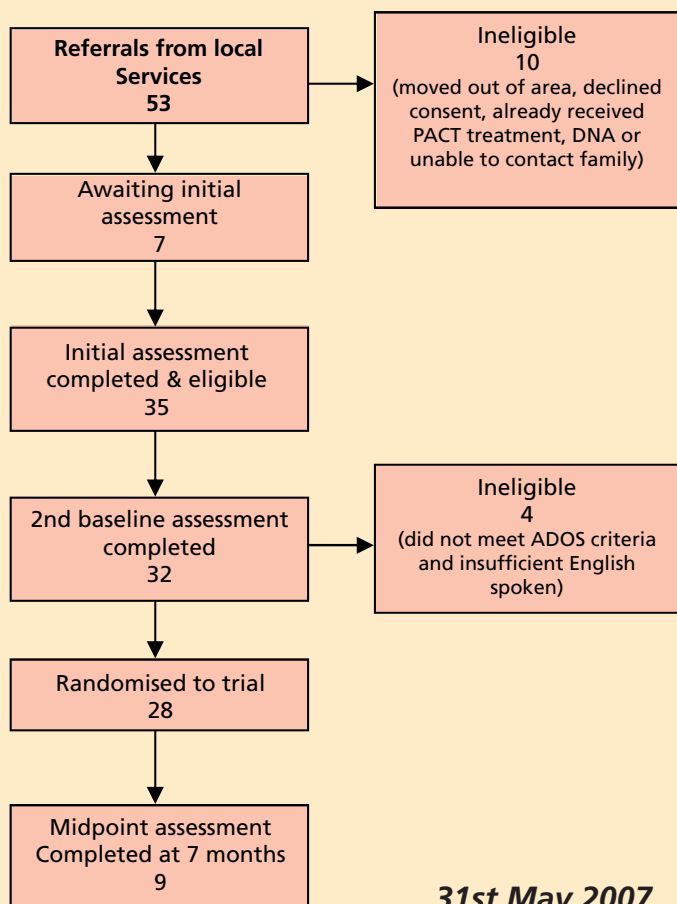
PACT is the largest autism trial internationally, following gold standard research methods to date. This trial is at the forefront of autism research and a fantastic opportunity to extend quality early intervention into routine health care practice based on rigorous research. This is a tremendous opportunity to prove the value of early autism specific intervention which embraces parents as co-therapists. We are at a critical stage where your help is needed in recruiting children to ensure we continue to meet targets for the trial. The outcome of this trial will be disseminated nationally to all PCTs and has the potential to radically revise existing practice in providing comprehensive services for families with young children who have autism. Many thanks to all the professionals who have supported the trial in referring families.

*Map of Great Britain showing Referral sites*



## Recruitment Update

There are now over 30 clinicians referring participants to the study from Newcastle, London and Manchester. Overall 156 participants have been referred of which 73 have been randomised to take part. We have detailed in the flow chart below the flow of participants through the study in your area.



## Contact the Team

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## DES System for Data and Data Error Reporting

We use a web based data entry system (DES) to store the data from the PACT trial. This was set up by the Mental Health Research Network (MHRN) in liaison with the PACT Data Co-Ordinator. Researchers at each site can access the system with an e-mail address and password via an NHS server. This ensures that the data from our study is secure and backed up. As the PACT study is a multi-site trial, this data entry system is very useful as data from all sites can be stored in one place. This will be helpful to us when we are ready to analyse the data.

## Assessing Participants to the Study

Families participating in PACT receive a comprehensive set of assessments on entry into the study. This includes state-of-the-art autism assessments, the Autism Diagnostic Interview, and the Autism Diagnostic Observation Schedule. Together these give us a detailed picture of the child's level of impairment in social interaction, communication, imagination/play and repetitive behaviours and restricted interests. We also carry out assessments of the child's language and prelinguistic abilities, both based on parental report and on direct observation. Children's non-verbal abilities are assessed using the Mullen Scales of Early Learning and the Vineland Adaptive Behaviour Scales.

In addition, our health economists have designed the PACT Service Use Schedules. These are interviews that we carry out with parents to obtain a picture of the services that the family have received. In collaboration with the National Autistic Society and focus groups we have designed a questionnaire which asks for parents' own feelings about their family life, and specifically, how they are coping with being the parent of a child with autism.