

Institution: The University of Manchester		
Unit of Assessment: 4 (Psychology, Psychiatry and Neuroscience)		
Title of case study: Transforming Autism Treatment Worldwide: the Manchester-led Paediatric Autism Communication Therapy (PACT)		
Period when the underpinning research was undertaken: September 2000 - December 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by the submitting HEI:
Jonathan Green	Professor	2005 - date
	Senior Lecturer	2000 - 2005
Ming Wai Wan	Lecturer	2003 - date
Catherine Aldred	Honorary Lecturer	2006 - date
Kathy Leadbitter	Research Fellow	2016 - date
	Research Associate	2006 - 2016
Carol Taylor	Research Associate	2016 - 2019
Andrew Pickles	Honorary Professor	2010 - 2015
	Professor	2000 - 2010
Richard Emsley	Professor	2016 - 2018
	Senior Lecturer	2012 - 2016
	Research Fellow	2006 - 2012
Period when the claimed impact occurred: August 2013 - December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>University of Manchester (UoM) researchers developed an early childhood intervention, representing a paradigm shift by working directly through parents rather than exclusively with the child. It is the first treatment to have achieved sustained improvement in autism symptom severity before and after diagnosis and with improved parental well-being. Over 600 professionals in more than 21 countries have been trained to date and >80% with actual or planned implementation with multiple families. It has influenced policy guidance internationally and has been adapted and evidenced for low and medium income country settings. International survey evidence shows high acceptability, implementation and effectiveness.</p>		
2. Underpinning research		
<p>Autism is an enduring condition affecting over 1% of people worldwide (approximately 190,000,000 children), but without effective therapy to reduce its symptoms. UoM research 2000-2020 led a treatment discovery and translational programme of innovative autism treatment. From 2000, a UoM pre-school autism intervention, based on developmental theory showed promise in pilot work [1]. MRC awards (Green as CI, Leadbitter, Aldred, and Taylor in the team) from 2006 allowed further development and testing of this Paediatric Autism Communication Therapy (PACT) in a UK consortium</p>		

including Newcastle University, Kings College and Guys and St Thomas' Hospital, London. The three site (Manchester, London, Newcastle) MRC PACT trial, the largest then undertaken in autism, led to two Lancet publications [2,3], reporting a **significant reduction in autism symptom severity for the first time**, sustained for six years after the end of therapy. At the start of treatment, 50% of the controls and 55% of those in PACT intervention were severely autistic; at follow-up, the proportion was 63% in the control group but 46% in the PACT group. Publications on Health Economics, measurement, parent mental health and well-being related to PACT treatment have followed; further NIHR/MRC Efficacy and Mechanism Evaluation programme trial of extension of PACT into schools is ongoing.

From 2006-12, Pickles, Emsley and Green were part of two MRC methodology programmes developing analyses of causal inference and mediation in trials of complex interventions in mental health; methods were applied to the PACT trial, in the first **mechanism analysis in autism intervention** [4], which demonstrated the mechanism of action of the treatment through parents in a way that supported its theoretical rationale and provided a platform for refinement and adaptation of the therapy for other settings.

The 'prodromal' period before autism emerges from two to three years of age is an important target for **prevention therapy**. Leading another national consortium from 2012, Green developed a related briefer treatment method, building on new infancy developmental science from UoM and Birkbeck, London, to target these early prodromal processes in 9 months old infants at high familial risk of autism. The findings [5] mirrored PACT, showing for the first time that a prevention intervention in autism could modify the severity of emergent autism symptom trajectories over three years. This work is currently being reproduced in Australia.

Global health With approximately 1% prevalence across the world, most autistic children live in the global south (approximately 6,000,000 in India alone) and have no access to evidenced therapy. In 2012, Green's group partnered with colleagues in South Asia to adapt and test the PACT intervention in low and middle income settings; the first time an evidenced autism treatment had been systematically adapted in this way. This collaboration showed [6] that this technical intervention could be successfully delivered by non-specialist workers in remote settings, with treatment fidelity and proximal outcomes equivalent to UK trials. Green is now leading a large MRC/Wellcome/Department for International Development Joint Global Health Trial of this approach at scale in India.

3. References to the research

1. **Aldred, C, Green, J, Adams, C.** A new social communication intervention for children with autism: pilot randomized controlled treatment study suggesting effectiveness. *J Child Psychol Psychiatr* (2004), 45,8, 1420-1430. <http://dx.doi.org/10.1111/j.1469-7610.2004.00338.x>
2. **Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, H., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., Barrett, B., Temple, K., Macdonald, W., Pickles, A., and the PACT Consortium.** Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *The Lancet* (2010), 375(9732), 2152-2160. [http://dx.doi.org/10.1016/S0140-6736\(10\)60587-9](http://dx.doi.org/10.1016/S0140-6736(10)60587-9)
3. Pickles A., Le Couteur A., **Leadbitter K.**, Salomone E., Cole-Fletcher R., Tobin H., Gammer I., Lowry J., Vamvakas G., Byford S., **Aldred C.**, Slonims V., McConachie H., Howlin P., Parr J., Charman T., **Green J.** Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet* (2016), 388: 2501-09. [http://dx.doi.org/10.1016/s0140-6736\(16\)31229-6](http://dx.doi.org/10.1016/s0140-6736(16)31229-6)
4. **Pickles, A., Harris, V., Green, J., Aldred, C., McConachie, H., Slonims, V., Le Couteur, A., Hudry, K., Charman, T. and the PACT Consortium.** Treatment

mechanism in the MRC preschool autism communication trial: implications for study design and parent-focussed therapy for children. *J Child Psychol Psychiatr* (2015), 56: 162-170. <http://dx.doi.org/10.1111/jcpp.12291>

5. **Green, J.**, Pickles, A., Pasco, G., Bedford, R., **Wan, M.W.**, Elsabbagh, M., Slonims, V., Gliga, T., Jones, E.J.H., Cheung, C.H.M., Charman, T., Johnson, M.H. and The British Autism Study of Infant Siblings (BASIS) Team. Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *J Child Psychol Psychiatr* (2017), 58:12 1330-1340. <http://dx.doi.org/10.1111/jcpp.12728>
6. Rahman A, Divan G, Hamdan S, Vajaratkar V, **Taylor C, Leadbitter K, Aldred C**, Minhas A, Cardozo P, **Emsley R**, Patel V, **Green J**. Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in South Asia in India and Pakistan (PASS): a randomised controlled trial. *The Lancet Psychiatry* (2016), 3:128-36. [http://dx.doi.org/10.1016/S2215-0366\(15\)00388-0](http://dx.doi.org/10.1016/S2215-0366(15)00388-0)

Evidence for the quality of the research The programme was supported by MRC project grants G0401546 (2006-10) GBP1,300,000; MR/K005863/1 (2012-15) GBP1,000,000; MRC/NIHR EME award 13/119/18 (2016-19) GBP1,700,000; MRC/Wellcome Trust/DfID Joint Global Health Trial award (2018-22) GBP2,000,000; and NIHR HTA 17/80/09 (2019-23) GBP1,400,000.

Paper [3] was chosen as a NIHR 'Signal study' for its 'high quality design and relevance to UK decision makers' [B]; Altmetric attention score 1133 (7/2020) with 156 citations, 443 tweets; Radio 4 'Today' programme interview with Green on the results (26/10/16). Paper [5] Altmetric Attention 285, 83 citations. [3,5] independently voted as two of the top ten autism papers internationally for their year (sfari.org and Autism Speaks). [6] Voted one of the top 10 autism papers internationally for 2015. Green has given numerous international keynotes on this work.

4. Details of the impact

Context

Autism is a priority condition worldwide because of its >1% prevalence and enduring societal impact; estimated UK health and societal costs (GBP32,000,000,000 per annum) exceed those of stroke, heart disease and cancer combined. The UK's autism research charity Autistica states "*PACT is the only well-evidenced therapy that has the potential to improve a child's social communication skills in a sustained way as they develop and therefore alter their longer-term trajectory in life*" [A].

Pathways to Impact

Following publication in leading scientific journals, including two Lancet papers, NIHR 'Signal Study' status [B], and global media interest, international professionals have responded with replication and extension plans. In 2017, Green formed a spin-out not for profit community interest company from the University (IMPACT; Community Interest Company (CiC) No 10902031) to formalise PACT training and support world-wide implementation; a systematic survey of its impact is below. The work has been referenced in national and international treatment guidance documents (see (iv) below). Funded implementation trials internationally have involved over 1,300 families and ongoing testing of an online remote PACT delivery increases dissemination.

Reach and significance of the impact

(i) Benefits to people with autism and their families [C]. The PACT therapy works with parents using structured video-feedback techniques to help them recognize better their autistic child's altered communication. Working through parents rather than with the child (the traditional approach), is efficient of therapist time, empowers parents with enhanced skills, embeds the work into family life, improves family self-care and resilience and creates sustained change in child symptoms [C,3]. International survey of PACT training (2020,

n=332) [D], found strong parental endorsement of relevance and acceptability (median 6/7; 1= 'strongly disagree', 7='strongly agree'), therapeutic improvement for child (5.8/7), feasibility in everyday life (6/7) and family wellbeing (6.5/7).

Parent reports on the experience of receiving PACT therapy were evaluated through independently conducted interviews [D]: *"I put my eyes behind [child's name]' eyes and I just imagine for a minute that I am in [child's name]'s little head and try to look at it from his angle...and you probably react totally different to the way you would initially react, because you have looked at it from his point of view"; "We are so pleased with the progress he's made, it has been fantastic. I think the PACT trial was huge, it was hugely important to him. And it was hugely important for the whole family, it is kind of a family confidence it gave the whole family really"; "And my husband, my family all suddenly saw [child's name] as opposed to the autism".*

(ii) Community health impact. PACT implementation has been in close collaboration with families and service users. The team co-developed [E] the first user-nominated measure of treatment outcome in autism now being used by 23 clinical teams in 15 countries and 12 languages and in three other major research trials (262 discussion tweets reaching 398,000 people internationally). A UK trial of education adaptation has involved 200 schools and nurseries; treating 120 children and skilling up an equivalent number of teaching assistants for application to other pupils. It has attracted investment from Greater Manchester Health and Social Care Partnership of GBP100,000 for a Greater Manchester-wide implementation.

(iii) Global education and training for healthcare professionals. IMPACT CiC has trained over 600 new professionals from 21 countries to date; 60% responded to a 2020 survey [D]: >70% had used the training and >60% had already implemented the therapy with a median of four families and another 19% intend to shortly. Professionals rated high PACT relevance and acceptability with median score 6.7/7 (n=110) reflecting improvements in how they communicate with a child with Autism Spectrum Disorder and in how they can aid parents to more empowerment.

(iv) International guidelines and changes to practice. Based on PACT research and one other US group, the NICE Clinical Guideline 170 on 'Autism spectrum disorder in under 19s: support and management' (NICE August 2013) [F] issued a 'consider' recommendation for early 'social communication' intervention, working through carers or teachers, for the core symptoms of autism; the only treatment approach so advocated. Internationally, Belgium included the same evidence and recommendation [G] and it is now known that upcoming French national guidance for autism will recommend PACT intervention. PACT was highlighted as one of the few evidenced treatments for autism in the 2017 UK 'National Autism Project' [H], the 2020 UK Parliament POSTNOTE on Autism [I], plus nominated treatment for autism symptoms in the DH 'Improving Access to Psychological Treatment' (IAPT) curriculum for Autism and Learning Disability. The UK research charity Autistica's independent evidence summary on PACT for NHS providers, commissioners and professionals recommends the national implementation of PACT [A].

(v) Global impact including in low and medium income countries. The PACT therapy has been adapted for use in low and medium income countries to be delivered by non-specialists [4] and a large scale up trial is underway within the Indian health system, with potential to reach the estimated 6,000,000 children with autism in that country. Further implementation studies are planned or underway in US, Australia, Hong Kong, China, Brazil, Denmark, France [J]. Progress to date was evidenced in the first IMPACT international symposium in 2020 [J].

5. Sources to corroborate the impact

- A. [Evidence Summary and recommendations for PACT treatment](#) Autistica 2018. Changes to Practice. Independent Evidence Summary published by the research

charity Autistica 2018, highlighting the evidence for PACT intervention and recommending its implementation in all areas throughout the NHS.

- B. <https://evidence.nihr.ac.uk/alert/parent-focused-therapy-has-some-long-term-benefits-for-children-with-autism/>; Pathways to Impact. Notification of NIHR 'Signal Study' status for the 2016 Lancet PACT trial publication, for its quality and relevance to UK decision makers.
- C. [PACT website](#). Benefits to autistic people and families. Evidence on the impact of PACT and iBASIS therapy for children and families based on extensive archived correspondence with the PACT team, and from independent media reports and commentary.
- D. Leadbitter K, Macdonald W, Taylor C, Buckle KL. Parent perceptions of participation in a parent-mediated communication-focussed intervention with their young child with autism spectrum disorder. *Autism*. 2020;24(8):2129-2141. Evidence of benefits of PACT therapy for children and families from independently conducted qualitative interviews with parents after receiving PACT therapy.
- E. Leadbitter et al. The Autism Family Experience Questionnaire (AFEQ). *J Autism Dev Disord*. 2018 April; 48, 1052–1062. Evidence of the PACT team co-production with Service Users; resulting in the first validated user-nominated outcome measure to be published in autism.
- F. ['Autism spectrum disorder in under 19s: support and management'](#) Guidelines and practice. Formal 'consider recommendation' for social communication treatments including PACT, within NICE Clinical Guideline 170 on autism treatment for under 19's, 28 August 2013.
- G. https://kce.fgov.be/sites/default/files/atoms/files/KCE_233_Autism_Report.pdf Belgian National Clinical Practice Guideline for Autism 2014 includes review and recommendations for evidence-based practice citing PACT evidence.
- H. <https://nationalautistictaskforce.org.uk/national-autism-project>. Changes to Practice. PACT highlighted as one of the few well evidenced interventions for autism in the UK National Autism Project 'Autism Dividend' report; launched in House of Commons with the all-party parliamentary committee on autism.
- I. <https://post.parliament.uk/research-briefings/post-pn-0612/>. Changes to practice and national influence. PACT cited for evidence-based practice in a government Research Briefing POSTNOTE 612 on Autism, January 2020.
- J. Record of the symposium presentation of systematic survey data collected 2019 - 2020 on the impact of international PACT training across 21 countries for parents, professionals and health delivery services.