



The Children's Trust Research Governance Committee

Progress Report April 2018

Introduction

The research team has had a positive year and achieved our 2013-2018 research strategy. The new 5-year strategy is in draft following consultation with a number of families.

The Research Committee (now known as Research Group) has continued to meet monthly.

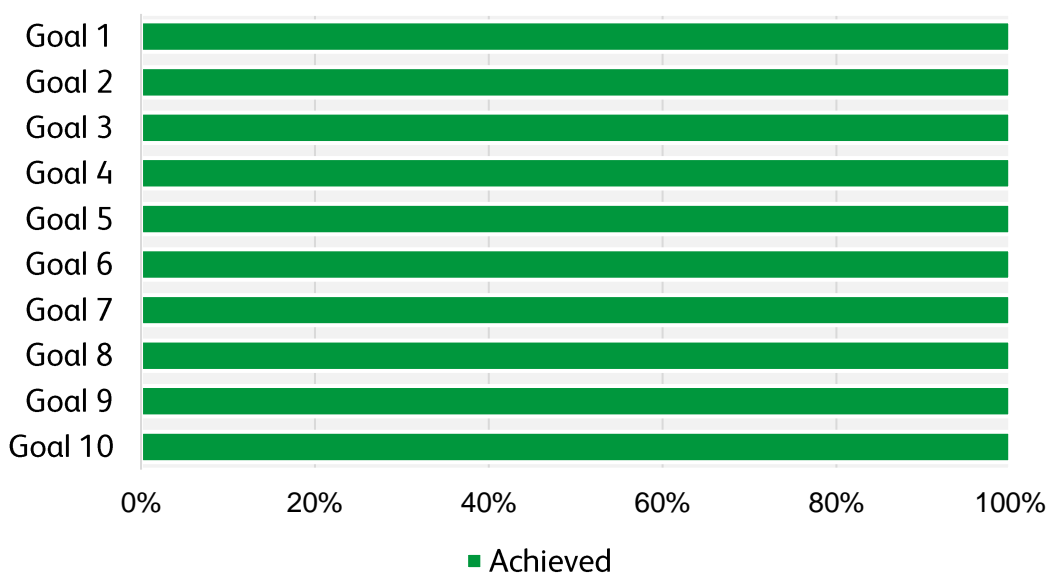
We have particularly seen the benefit of the appointment of our Research Nurse, Dr Kathy Davis. Gemma Kelly has altered her role to include 2 clinical days and we have been happy to welcome Colin Hamilton, research physiotherapist one day a week on a 1 year fixed term contract. Unfortunately our librarian is required to return to the USA and we have begun to seek a replacement.

We are delighted to have secured an honorary contract for Dr Rob Forsyth.

Dr Carolyn Dunford has taken a position as Lecturer at Brunel University, London and David Knivett has joined the organisation as Head of Clinical Education and Research.

Performance Indicators

Progress Against Research Strategy 2013-18



Goal 1 to develop the evidence base through research programmes that enable the development of more effective clinical care and therapy for children and youth with brain injuries

The Children's Trust continue to have an active programme including 23 projects. More clinical and non-clinical teams have become involved and we have a broad portfolio of audit, service evaluation and research. The new Brain Injury Community Service model was launched in January 2018. It is underpinned by last year's research study and incorporates a strong research element of monitoring and surveillance.

We have started a joint initiative with Surrey Children's Services to develop pathways and means of delivering long term rehabilitation in the community.

Goal 2 to develop the evidence base through research programmes that investigate strategies to enable the development of more effective education for children and young people with profound and multiple learning difficulties

Comments: Devina Ferullo continues to build research relationships within The Children's Trust and externally. A collaborative project (SMARTY) has been extended to include children and young people with profound and multiple learning difficulties. A number of service developments and research ideas have been formulated amongst the multidisciplinary team. Evidence summaries have been written and the team have had their work accepted at national conferences.

Goal 3 To develop methods of describing rehabilitation interventions

Comments: New rehabilitation input tool Paediatric Rehabilitation Ingredients Measure (PRISM) receiving interest among rehabilitation community

| Action to meet Key Objectives of Goal 3 by March 2018 | Responsible Person | Target Date | |
|---|--------------------|-------------|----------|
| Support NIHR grant application | LW,CD | Dec 2017 | Achieved |
| Submit PRISM paper for publication | LW,CD, KD, GK | Aug 2017 | Achieved |
| Present PRISM at IPBIS conference | LW,CD, KD,GK | Sep 2017 | Achieved |

Goal 4 to develop expertise in measuring outcomes of rehabilitation

Comments: The FIM+FAM publication (collaboration with Brunel University) has received a lot of interest and has already been cited. We presented The Children's Trust data for childhood stroke at international conference and have prepared a manuscript for submission to a peer review journal. We presented preliminary analysis of our full UKROC dataset at international conference. Dr Rob Forsyth is carrying out a full analysis and we are preparing a manuscript for submission. We continue to be invited to present at local/national training events to share our experience of rehabilitations outcomes e.g. Goal Attainment Scaling.



| Action to meet Key Objectives of Goal 4 by March 2018 | Responsible Person | Target Date | Progress |
|---|--------------------|-------------|----------|
| Submit UKROC data for publication | LW, KD, GK | Feb 2018 | Draft |

Goal 5 to support and develop multi-disciplinary professionals at The Children’s Trust in undertaking clinical research

The 2017 Research Day was encouraging as Kathy Davis supported many nurses to present their work. Following the success of the day, the school nurses were supported to publish their health promotion project and were nominated for the Burdett Nursing Young Person’s Health Award. They were successful in achieving this important award. Due to her success in reaching the final stages in nursing award, Clair Seeruthun harnessed a new confidence and been successful in gaining a promotion to House Manager.

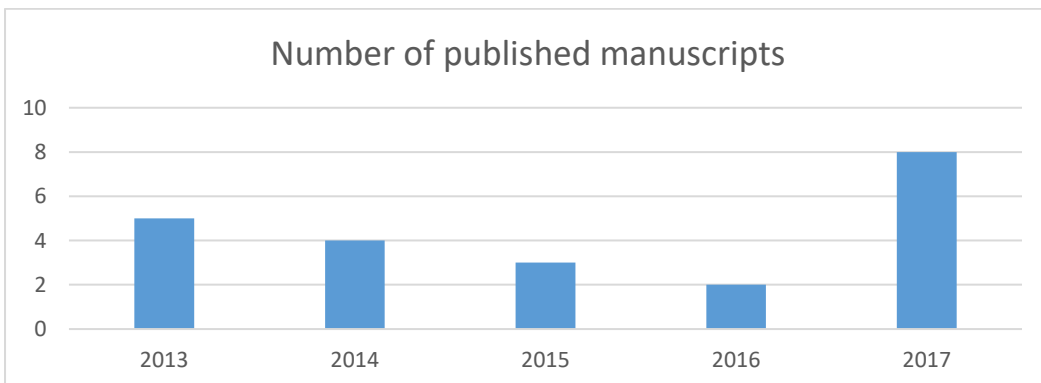
Tim Grove (Quality Improvement lead) has completed an MSc in Strategic Quality Management at University of Portsmouth with distinction. Melanie Burrough (OT professional lead) completed an MSc. Gemma Costello (Psychology professional lead) has completed a PGDip in paediatric neuropsychology. Helena D’Angelo continues an MSc in Leadership and Management in Health Information at Kingston University. Rachel Garrod (physio) completed the Chartered Society of Physiotherapists leadership development programme. Helle Mills (OT) attended a National Institute for Health Research day at Royal College of Occupational Therapists and is preparing an application for a clinical academic fellowship. Lorna Wales is mentor to an applicant from the White Lodge Centre who also pursued this application.

Lorna has continued with a British Academy of Childhood Disability (BACD) Castang fellowship developing future research leads in neurodisability. Professor Juliet Goldbart has been her mentor. Lorna is preparing a grant submission for a long term rehabilitation follow up study.

Goal 6 to disseminate research findings and evidence based practice to national and international audiences to raise awareness of the work of The Children’s Trust with scientific, clinical and educational professionals

Comments: The research and clinical teams continue to present at unidisciplinary conferences and are invited to speak at a number of events. In addition to having abstracts accepted at international multidisciplinary conferences, colleagues are also being invited to co-present with international researchers (International Paediatric Brain Injury Society, World Federation of Neurorehabilitation). One such presentation was with Professor Goldbart “From research to practice and from practice to research” at 20th European Academy of Childhood Disability (EACD) meeting, Georgia.

The Children’s Trust Conference and Annual Research Day 2017 were well attended and positive feedback was received. This year research day will be split between a research focussed day and a quality improvement day where Special Interest Groups will be encouraged to share their work. We are delighted to have a greater number of publications this year (see table). The full references are listed at the end of the report.



Goal 7 to monitor research activity across The Children’s Trust

Comments: Research group meetings continue to be held on a monthly basis, reporting to The Children’s Trust Clinical Governance and Safeguarding Committee. Research governance has improved with clearer systems and processes. Many projects have been archived and two projects have been closed where little progress had been achieved. The 23 active projects remaining can be monitored more easily by the research group.

Goal 8 to establish a research culture across The Children’s Trust ensuring delivery of evidence based interventions

Comments: In partnership with the clinical teams we have finalised a large range of evidence summaries. We have been able to produce the first “evidence manual” to share with the clinical teams and we have shared the evidence summaries on The Children’s Trust website. The Brain Injury Community Service has a clear research direction and meets regularly to prioritise development of evidence summaries, data collection and analysis.

| Action to meet Key Objectives of Goal 1 by March 2018 | Responsible Person | Target Date | |
|--|--------------------------------------|-------------|------------------|
| Librarian to offer teaching sessions | BJ | Summer 2017 | Achieved |
| PDR objectives to include completion of an audit and involvement in EBP guidelines | Professional leads | March 2018 | Achieved/ongoing |
| To collaborate with professional leads to establish means of knowledge transfer | Research team and Professional Leads | March 2018 | Achieved/ongoing |

Goal 9 to establish comprehensive information resources specialising in the areas of brain injuries, multiple disabilities and complex health needs

Comments: The Teenage handbook has been launched. A manuscript of the Information Needs project has been accepted for publication and the authors are responding to reviewers’ comments. There are a greater number of information leaflets at The Children’s Trust. Our librarian recently posted a blog on The Brain Injury Hub to highlight a “call to action” report to the US Congress.

Goal 10 to establish and maintain research partnerships with external organisations

Comments: We continue to benefit from the ongoing collaboration with Dr Rob Forsyth and Dr Margaret Mayston in both a research and clinical capacity. Although we continue to develop collaborations and partnerships, this year has seen us become more strategic about relationships. The ones that are more closely aligned to our work and strategic objectives are becoming more meaningful.

- University College London (Dr Margaret Mayston; education partnership)
- Manchester University (Professor Goldbart)
- Temple University Philadelphia (Wendy Magee)
- Bloorview Children’s Hospital Canada (Family Needs Questionnaire-Paediatric version)
- Kennedy Kruger Institute, USA (Physical Abilities Measure)
- Brunel University, London (My Health, My Voice)
- Newcastle University (Dr Rob Forsyth)
- Steering committee on projects at Great Ormond Street Hospital and Oxford Brookes University
- Kings College London (Sally Nissen)

Publications

Kelly, G. and Shanley, Functional electrical stimulation to improve upper limb function in a child with an acquired brain injury: A single case experimental design study. *International Journal of Therapy and Rehabilitation* (early online)

Nissen S, Purssell E, Shaw K, Bailey C & Efstathiou N and Dunford C (2018) Impaired mobility associated with an increased likelihood of death in children: a systematic review *Journal of Child Health Care* Mar;22(1):147-158

Kelly G Using single case experimental design in physiotherapy research. *Association of Paediatric Chartered Physiotherapists Journal*

Forsyth, R. Young, D. Kelly, G. Davis, K. Dunford, D. Golightly, A. Marshall, L. Wales, L. (2017) A Paediatric Rehabilitation Ingredients Measure (PRISM) for identification of paediatric neurorehabilitation content *Developmental Medicine & Child Neurology* Early view 21.12.17
<http://onlinelibrary.wiley.com/doi/10.1111/dmcn.13648/abstract>

Austin D, Frater T, Wales L, Dunford C.(2017) Capturing changes in functional ability in older children and young people with acquired brain injury: Responsiveness of the UK FIM+FAM *British Journal of Occupational Therapy*
<http://journals.sagepub.com/eprint/ur74ijukQvi8xSfxj5e2/full>

Titchener, A. Dunford, C. Wales, L. (2017) A reflective case review: Re-learning handwriting after a Traumatic Brain Injury *British Journal of Occupational Therapy* accepted 4.12.17

Davis, K. Carter, S. Myers, E. & Rocca, N. (2018) Health and emotional well-being matters: health promotion program for Children and Young people with PMLD and complex health care needs. *Nursing Children and Young People* Feb 7;30(1):28-34

Davies G, Jordan S, Brooks CJ, Thayer D, Melanie M, Morgan G, Allen S, Garaiova I, Plummer S & Gravenor M (2018) Long term extension of a randomised controlled trial of probiotics using electronic health records. *Scientific Reports*. 8:7668