

The Children's Trust Research Governance Committee

Progress Report June 2019

Introduction

The Children's Trust Research Governance Committee is delighted to welcome new members this year. Dr Vijaya Ganesan, Senior Lecturer in Paediatric Neurology, Great Ormond Street Hospital has kindly agreed to be the chair of the committee. Amy Muggerridge, Research Manager, Young Epilepsy and Dr Daniel Lumsden, Consultant in Paediatric Neurology and Complex Motor Disorders, Evelina London Children's Hospital have agreed to join as members.

The research team appointed Colin Hamilton, physiotherapist for a 1 year contract as research physiotherapist. We will continue to offer this opportunity to those on a clinical academic career pathway. We also recruited a part-time specialist clinical librarian.

The research group has continued to meet monthly (see attached documents). This year the team trialled a new format for the annual research day. Two short days were delivered. One had a focus on quality and service evaluation related projects and the other focussed on research related projects.

The new 5-year research strategy was accepted by The Children's Trust Board of Trustees at their meeting in November 2018. The Children's Trust Research Governance policy will be reviewed at this meeting.

The research strategy has two key objectives that focus on **developing the evidence base** and **moving evidence into practice**. This report will review progress towards the delivery of these objectives (see attached document).

Developing the evidence base

To develop and maintain the evidence base through research programmes that enable more effective clinical care, education and therapy for children and young people with brain injury and neurodisability.

Progress on key factors

Research portfolio

Our current research programme has **21 projects** of which **11** include an external national or international collaboration (see Appendix A). This year shows a broader range of clinical disciplines represented within the research programme.

The research team has developed a programme of quality, service evaluation and research activity. There has been a wide range of activity this year that has supported professional development across the organisation which has led to the creation of a manual evidence summaries, clinical audit against new policy, and service evaluation in line with best practice.

The Brain Injury Community Service has successfully introduced new data management systems. These new systems will support the reporting and evaluation of the service, in addition to adding to a significant source of data that can be used for future research projects with data for children who move into adulthood. We have a new academic collaboration with Professor Mark Pearce, Newcastle University who was able to identify opportunities for MSc and PhD collaborative projects in the future.

A number of initiatives at The Children's Trust have moved closer to innovation and technology research. The appointment of Colin Hamilton this year has strengthened the links with external academic collaborations and funding bodies, while internal appointments and structural changes have resulted in a dedicated assistive technology (AT) team. This team supports the development of best practice of technology in clinical practice in addition to scoping innovations for technology based solutions for intervention.

We were ambitious to have a research programme that included a technology project on the portfolio. New learning and networking at conferences has led to increased awareness of the role of robotics and Virtual Reality (VR) in motor rehabilitation. These innovations are currently being developed and trialled within the clinical services with close links to the research team. The therapy team has a project with a VR company called MindMotionGo and is scoping the role of robotics within the rehabilitation programme.

The Children's Trust has collected a large volume of rehabilitation data for NHS England as part of the National Specialised commissioning contract (UK Rehabilitation Outcome Collaborative-UKROC). Rob Forsyth and Colin Hamilton have supported Tim Grove and the research team to

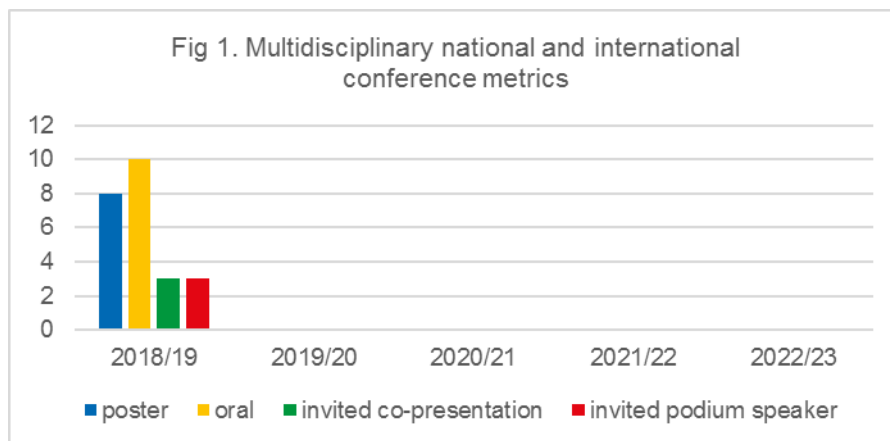
complete a full analysis of these data and produce two reports. One technical report will be presented to NHS England and the other manuscript will be submitted for peer-review publication. In addition, the ongoing collection of data for UKROC has given the opportunity to interrogate subsets of data including childhood stroke and encephalitis in response to clinical questions raised at forums such as post-discharge reflection meetings with the team.

Publications and presentations

This year we have published **five** peer reviewed publications and **two** professional publication articles (see publication list at end of report). A further seven manuscripts are in preparation. One is awaiting resubmission, the others are in final draft and will all be submitted to peer review journals in the coming months.

We have co-written a commentary paper for publication in an upcoming issue of NeuroRehab Times with colleagues at the Cambridge Centre for Paediatric Neuropsychological Rehabilitation. Both centres (The Children's Trust and CCPNR) published a goals paper this year and the results have been consolidated to reflect the goal setting priorities of children, young people and families at different stages of recovery.

The research team continue to support the clinical team to have a presence at key multidisciplinary national and international conferences. In the past year we are particularly pleased to have been invited to co-present with international academic partners at European Academy of Childhood Disability (Lorna Wales) and International Paediatric Brain Injury Society (Gemma Kelly, Jonathan Pool, Gemma Costello, Birgitta Norton, Liz Roberts) conferences. See figure below for year 1 metrics.



Collaboration

Kathy Davis has continued to lead the ongoing collaboration with NHS Improvement. Our acuity project has entered the third phase with NHS England facilitators coming to The Children's Trust to deliver education and training to instruct the workload and staffing data collection. This will lead to the development of a bespoke acuity tool.

Colin Hamilton completed a National Institute of Health Research (NIHR) MRes while working at Addenbrookes, Cambridge and is preparing for a PhD fellowship. During the year Colin at The Children's Trust he was able to support further collaboration between The Children's Trust and NIHR Children and Young People MedTech Co-operative (NIHR CYP MedTech).

Through the BACD-Castang programme Lorna has benefitted from the support and mentorship of senior academics and Professor Mark Pearce, Professor of Applied Epidemiology, Health Protection Research Unit, Newcastle University has now joined the research team for the long term participation study.

External roles and memberships

Gemma Kelly has been accepted as a member of Physiotherapy Research Society to serve a term of 3 years. Sammy Randall (occupational therapist) has been invited to join the steering committee of an NIHR funded project with PenCRU - Improving continence for children and young people with neurodisability (ICON). As a result of collaboration and networking, Sammy has been invited to present to the Evelina Children's Bladder Clinic and has been approached to consult in product development of a new toileting product with Leckey and has become a professional advisory panel ERIC bladder and bowel charity.

In addition to her role as Newsletter Editor for European Academy of Childhood Disability, Lorna Wales (3 year term to be renewed at EACD meeting June 2019) has been accepted to be on the communication committee of the newly established International Alliance of the Academies of Childhood Disability (IAACD).

Funding

Research funding from The Private Physiotherapy Educational Foundation was used to complete The Rhythmic Auditory Stimulation (RAS) project. This project is complete and has been disseminated at international conference. The manuscript is in the final draft stage. This study using multiple baseline single case experimental design (n=4) found that RAS may be effective in targeting gait speed and quality, and could be considered alongside other gait interventions.

The MuSICCA project has secured part funding. These funds will be released when the remaining funds for the project are secured. This project has ethical approval and is ready to start data collection.

Two bids have been submitted this year for peer reviewed research funding to support the long term participation study of children and young people from the residential rehabilitation programme (Sparks and Sir Halley Stewart). The Sparks application reached the second round but both applications were ultimately unsuccessful. Further funding opportunities will be explored in partnership with the fundraising team at The Children's Trust.

Moving evidence into practice

To champion and nurture an increasing research culture across The Children's Trust to deliver evidence based services.

Progress of key factors

Evidence based informed practice

Teams have been actively involved in developing more evidence summaries. Version 2 (2019) has **37 evidence summaries** under subheadings of Approaches; Clinical issues; Functional: cognition, psychological, gross motor, upper limb, assessment and management; Technology/ environmental. **All of the clinical teams** are represented in the development of the evidence summaries. These have been well received within the organisation and recognised within clinical networks externally. A PDF version will be posted on The Children's Trust website.

In order to establish the level of evidence based practice at The Children's Trust, a baseline assessment and audit were carried out. An EBP evaluation tool was trialled with a number of new starters to the organisation but reference data are not available to enable interpretation. Additionally, an audit of ten clinical notes and reports was carried out to review evidence of reporting of evidence based practice. While there was a good level of clinical detail in the notes and reports, the language of evidence based interventions was not overtly used.

The restructuring of the Research and Quality showcase days were well received with positive comments about the content and standard of presentations

- *“Great range of speakers. The format change worked really well. Great diversity of projects presented.”*
- *“Having external speakers really added to the day and provided a lot of interest”*
- *“It was great to see that quality and constantly trying to improving things is being embedded across all areas of our work. This is not just lip-service, we are really trying to learn and develop. Very inspiring.”*
- *“It was hugely informative. It highlighted the bits of work that people are doing in the background and how important it is to know about these so that we can all work as one”*

Quality Improvement Lead (Tim Grove) introduced quality improvement templates at the Quality Day and showcased how projects moved through the audit cycle, service evaluation to research. Oral health project is a good example of quality improvement and action research in practice. Initial audit; development of policy; screening and assessment; and the embedding best practice at The Children's Trust.

Helen Lynott (librarian) is leading a training initiative across clinical groups including preceptorship nurses, new starters, Clinical Education Team and individuals. In addition she is updating the library holdings, making the library more accessible to professionals and families and is actively participating in the search methodology of literature reviewing and publication.

Fellowships, leadership and academic training

Lorna Wales has completed a 2 year training/development fellowship with British Academy of Childhood Disability-Castang. The aim of the programme was to develop research leadership in children's neurodisability.

Three internal and external OT candidates of the NIHR clinical academic career pathway have received mentorship from Lorna Wales. The two external candidates work in local services in Surrey and one of the internal candidates (Helle Mills) received internship funding to complete this stage of the programme. Lorna is receiving support from the NIHR Research Design Service to make an application at the advanced clinical fellowship level of this programme.

The research team continue to link with clinicians who undertake post-graduate training within the organisation. Helena D'Angelo completed an MSc in Leadership and Management in Health Information at Kingston University. Two house managers are about to start post-graduate study to MSc level (Michael Humphrey-Jones, Claire Seeruthun) and one of the practice educators is completing a PGCert (Carla Chadwick).

Debbie Wilkinson became a Speech and Language Therapy (S<) champion with seconded 0.5 days to the research team. She completed a project analysing routine S< data which has been presented at conference and prepared for publication. She has recently accepted a research position at the Royal Berkshire Hospital, Reading.

Two staff are involved in external leadership development. Alison Fletcher is completing an Allied Health Professional leadership programme and Sammy Randall has secured funding from Elizabeth Casson Trust to complete a leadership development project. The Lead Rehabilitation Nurse (Kayleigh Goddard) is negotiating with the Royal College of Nursing for band 5 nurses to receive leadership training.

The range of clinical teams involved in service evaluation and research has increased this year. One of the social work trainees has developed a research protocol which will be taken forward with the Social Work Lead (Sharon Evans) and an academic at London South Bank University (Michelle Evans). Dr Vijay Palanivel is involved with 2 service evaluation projects. The psychosocial team have consulted on the Return to Activity study and Long-term follow up study

Teaching

Teaching takes many formats and the research team are regularly involved in delivering training and workshops both internally and externally. This includes a short seminar series on research methods and skills, therapy based learning and participation in Multidisciplinary teaching. The research team are able to offer mentorship, supervision and profession specific teaching.

Staff comment positively on the interactive research information in the research space. Poster presentations are shared and key documents are regularly updated for interest.

Dr Lorna Wales, Research Professional lead

Publications 2018-19

Keetley R, Kelly L, Whitehouse WP, Thomas P, Bennett E, Chow G, **Fletcher A**, Williams J. Early discharge and rehabilitation in paediatric acquired brain and neurological injury: a transferable model. *Archives of Disease in Childhood - Education and Practice* Published Online First: 20 October 2018. (Impact factor 1.590)

Kelly G, Dunford C, **Forsyth R**, Kavčič A. Using child- and family-centred goal setting as an outcome measure in residential rehabilitation for children and youth with acquired brain injuries: The challenge of predicting expected levels of achievement. *Child Care Health Dev.* 2019; 45: 286– 291. (Impact factor 1.699)

Dunford C, **Cobbold C**, Ray I, **Wales L**. The Information Gap for Children and Young People with Acquired Brain Injury. *Dev Neurorehabil.* 2019 Feb 6:1-8. (Impact factor 2.05)

Wales L, Sidebotham P, Hawley C. Self-awareness following a traumatic brain injury in childhood: a developmental perspective. *Brain Inj.* 2019;33(5):633-642. (Impact factor 1.808)

Kelly G, **Davis K**, **Wales L**. Regaining independent mobility doesn't always mean a full physical recovery: The presence of high level physical difficulties in children with acquired brain injuries. *Child: care, health and development* 2019 (Impact factor 1.699)

Kelly G, **Burrough M**, **Moys R** (2018) Facilitating evidence-based clinical decision making in upper limb rehabilitation *Children, Young people and Families Occupational Therapy Journal*, 22 (2)

Cundy K and **Hatfield I**. A Higher Level of support. *Bulletin*, May 2019

