

# The Children's Trust Research Governance Committee

## Progress Report June 2021

### Introduction

This research report covers a year of unprecedented changes imposed through COVID-19. The Children's Trust has had to navigate the course of the pandemic to date through three lockdowns and a number of restrictions, challenges to the organisation, clinical services and individuals.

This year introduces the updated Research Strategy 2020-2025. It aligns to The Children's Trust "Hope and Ambition" strategy and outlines how the research programme will support the organisation to achieve its three aims:

Aim 1 - Build on our specialist knowledge to grow our services in Tadworth and help more children and young people.

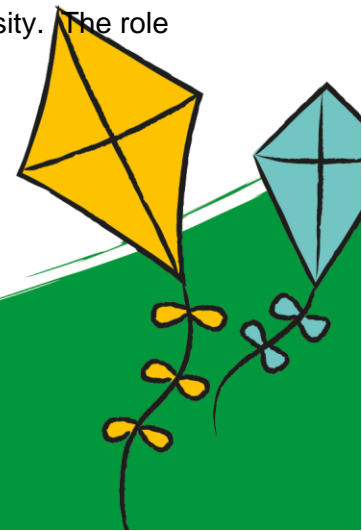
Aim 2 - support every child in the UK with an acquired brain injury.

Aim 3 - Improve outcomes for children and young people through integration of our specialist skills and approaches.

The Research Governance Committee is pleased to welcome Toby Mullins from The Children's Trust Board of Trustees as a permanent representative. The Brain Injury Community Service will appoint a new research link due to staff changes.

The research team have worked from home throughout this year. Dr Lorna Wales has continued in the leadership role of the research team throughout, reporting directly to Jayne Cooper, Director for Clinical Services (Chief Nurse). The Research physiotherapist was redeployed for part of the year to clinical duties in response to COVID-19. Three members of staff have taken a secondment opportunity with the Research Team in recent months. The Research Speech & Language therapist extended her contract for a further year (until October 2021) and increased to 2 days/week. An occupational therapist and educational psychologist have been seconded 1 day/week until October 2021.

The Research lead has secured an academic affiliation at Oxford Brookes University. The role is visiting researcher within the Faculty of Health and Life Sciences.



The research group have met monthly by remote videocall (see attachments for minutes). Attendance has been encouraging and new topics have been introduced to the meetings e.g. Excel hints and tips, external collaboration presentations.

The Annual Research Day is being planned for the Autumn. It will be a virtual event that will showcase research projects, encourage clinical staff to get involved in projects and a possible theme for the day will be 'Research and ethical issues in childhood disability'.

## Research portfolio

This year's research programme has included 23 projects of which 15 include an external national or international collaboration (see separate document).

### Response to COVID-19

During the first COVID-19 lockdown (March 2020) the research team consulted with the clinical and educational staff, asking for experiences and issues related to COVID-19 that they felt the research team could investigate. Firstly, the staff reported changes in professional roles and two members of the research team are carrying out a qualitative research study entitled "Role boundaries and team working during COVID-19 pandemic". The outputs will include an internal report of learning for the organisation and a manuscript for publication.

The second piece of work was a blog which captured momentum from World Health Organisation and international academics who highlighted the rights of the child during the restrictions of the pandemic. The blog particularly celebrated the creativity within The Children's Trust School team who had considered a Rights-Based Approach for children with neurodisability, including the right to play, education and access to family.

The third piece of work reviewed rehabilitation outcome data for children and young people who were admitted during the pandemic. Data was analysed from the 6 weeks before, during and after the lockdown. An internal report was produced that shared positive results of children continuing to meet rehabilitation outcomes during the lockdown. The report was well received by the clinical rehabilitation team and also with the Senior Leadership Team and the Clinical Governance and Safeguarding Committee.

As with other departments and services, the research team has experienced challenges and opportunities in this year. The increased use of technology for staff and colleagues has led to an increased attendance at research group meetings, the opportunity to contribute to webinars shared externally and recorded short tutorials for CPD in clinical practice. The consultant S&LT has responded to several external invitations to present webinars in the specialist field of swallowing, drooling and tracheostomy care. Remote conference attendance has been a cost saving to the team.

Among the challenges of remote working has been the reduced opportunity for the research team to have incidental encounters with staff teams across site and observe staff who may be emerging with potential academic interest. Likewise, there have been reduced opportunities to have incidental and informal interactions with children, young people and their families.

## Key research projects

MuSICCA is an international, multicentre project (validation of assessment for children and youth with Disorders of Consciousness) which now has USA funding and will be able to start more systematic data collection across centres.

AmBlt is a long term follow up study of children and young people from our residential rehabilitation service. This project has ethical approval and has started data collection. The first participants have been recruited and the steering committee had a first meeting. Further funding applications are ongoing.

Role boundaries and team working in a global pandemic was an internally initiated project. The Research nurse and Research speech & language therapist response has been to carry out a robust qualitative research study which will have generalisable messages for the wider clinical community.

The Returning to Physical Activity following an Acquired Brain Injury (ABI) project is complete and a manuscript is prepared for publication. This will go out once the Research physiotherapist returns from leave.

Patient involvement in research project has continued this year with some of the objectives and timelines altered to accommodate COVID-19 restrictions. Some of the connection work with families has been able to be accelerated whilst the planning of in-person events will be moved to later in the project. Research occupational therapist is working on this project as part of the secondment to the Research team. The researchers are interviewing families on the contact list to establish the type and extent of involvement that would be possible. Having started with the residential rehabilitation families, they will now reach out to families who access The Children's Trust School. There will be a cohort of parents with a range of skills including scientific knowledge, writing and blogging. A Brain Injury Hub blog was produced in direct response to one of these parent phonecalls.

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*Patient and Public Involvement (PPI) project is Wellcome funded for 3 years. As many as 80 families have agreed to stay in touch to support The Children's Trust to deliver a meaningful research programme. One parent is engaged in a knowledge translation activity which involves understanding the research of novel therapies and how it can apply to his son. This activity has become a co-production project with the research team, the librarian and the communications team as we investigate ways to make research accessible to all families. We co-presented this work at a recent international conference.*

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Dr Rob Forsyth, honorary researcher at The Children's Trust has continued to support the team with research methodology and data analysis. He has also continued to analyse rehabilitation input and outcome data including the PRISM, GMFM and PEDI-CAT and has co-authored manuscripts and conference presentations.

## Resources

**Staffing** The research team has FTE of 2.6 researchers. The research lead has continued to recruit to short term contracts and secondments to extend the range of clinicians involved in research activity and respond to staff requests within The Children's Trust and beyond for an opportunity to get involved in clinical research as part of a career path. This year a speech & language therapist and educational psychologist have added to the diversity of the programme.

**Library services** This has been a particularly challenging year for our clinical library due to staffing issues and demands, changed working practices and the need for additional space for workforce to be accommodated within COVID-19 distance guidelines. As a result, the library was relocated. The librarian has produced an informative and action focussed report to make best use of the library resources and support all of the clinical and educational teams over the next few years. The librarian is also part of the PPI project with a plan to co-work with parents and make scientific knowledge accessible to families. This activity will also be relevant to the 'parent offer' developments within The Children's Trust strategic Aim 1 programme.

The librarian has continued to collaborate with teams remotely this year. Clinical and educational professionals constantly access library support to develop evidence summaries on a range of topics. The librarian has produced the first in a series of pre-recorded video tutorials about accessing literature using online services. A new library facility is being discussed as part of the new build.

## Internal collaborations

The research team is represented on all of The Children's Trust strategic aims programmes (see above). The librarian and research team members are involved in accessing and critiquing literature to support service developments eg community rehabilitation service model, technology innovations. This year the research lead has been particularly involved in supporting the development of evaluation models and measures (Aim 2).

The research lead now has a regular (half termly) catch up meeting scheduled with key staff at The Children's Trust School. The PPI project is being rolled out to families who access TCT School. Families will receive an introductory newsletter on the school e-platform and the research lead will present at the next parent coffee morning.

The Measure of Process of Care (MPOC) is an international gold standard measure of how child and family centred an organisation is. These data are being collected across all clinical services and will allow the organisation to evaluate and improve service delivery. Additionally, The Children's Trust will be able to benchmark against other organisations. Research evidence shows that organisations that are child and family focussed have better child outcomes (see Aim 3).

We continue to evaluate outcome measures for children with brain injury and neurodisability. This year the therapists in The Children's Trust School evaluated the Participation and Environment Measure (PEM-CY) as a suitable tool for the school population. They analysed

some pilot data and presented at a national occupational therapy conference. PEM-CY is also the primary measure of the long term follow up study, AmBlt.

Quality Improvement and Service Improvement projects continue with cross professional involvement. The research team are collaborating with the team delivering The Children's Trust Aim 1 project. The librarian and research team support clinical and educational professionals to access and critique literature for potential innovations. The research team support projects that plan evaluation and outcome measures for innovations. The team have assimilated and shared research findings to inform projects e.g. family offer.

Members of the research team also lead and contribute to Clinical Excellence Network groups such as Disorders of Consciousness, pain management, participation. These multidisciplinary groups are responsible for ensuring best practice and excellence across clinical and educational services (Aim 1).

One of the medical consultants is supporting medical and multidisciplinary quality improvement projects with the rehabilitation teams. One of the doctors is developing a multidisciplinary project idea to review case notes of recent complex cases presenting with mental health issues following brain injury. The research team encourage and support this reflective thinking with the medical and other clinical and educational teams.

A new children and young person's matron has been appointed and the research team have had initial conversations about developing excellence and forward-thinking improvements in quality of care. The Quality Lead and Audit and research administrator continue to support and manage quality improvement projects and data management.

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*Continence is an important goal for many young people and their families. This year the occupational therapy team have been engaged in interdisciplinary problem-solving approach to this complex issue with the Research nurse, nursing and care teams, and the medical team. The working group are striving to embed excellence while also sharing best practice through webinar presentations. Continence is one of the top 10 research priorities for children with neurodisability (James Lind Alliance).*

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## External collaborations

The main external academic collaboration for this year has been with the MORES department at Oxford Brookes University. Professor Helen Dawes, leads the Movement Science Group based in the Faculty of Health and Life Sciences at Oxford Brookes University. She supports the Research lead with research skill development, reviews grant applications and advises on research methodology. Members of the Senior Leadership team and Aim 2 project lead met with Professor Dawes to consult on potential research opportunity within the strategic Aim 2

project. She encouraged The Children's Trust to consider NIHR funding streams and a potential PhD opportunity.

The informal regional research connections that have been nurtured in recent years has been enhanced this year through the launch of the NIHR Applied Research Collaboration, Kent, Surrey Sussex Starting Well: Children and Young People's Neurodisability Community of Practice. Two members of the research team were invited to attend the launch meeting in April 2021. This first meeting demonstrated that there are areas of common interest for future collaboration. The Research psychologist has been able to follow up a common interest in Video Interaction Guidance (VIG) with potential academic partners in the region.

The Therapy lead for school continues to collaborate with Associate professor Dana Anaby, Associate Professor, McGill University in the development of the Pathways and Resources for Engagement and Participation (PREP) intervention. She has contributed to the training programme and publications this year.

### **Student projects**

The research programme benefits from ongoing relationships with Brunel University, University of East London and the Institute of Child health (UCL). This year occupational therapy and physiotherapy masters students and psychology doctoral students have completed research projects using newly collected data and existing clinical datasets. These students are invited to share their findings to the research group and the Annual Research Day. They are encouraged and supported to write manuscripts for publication.

### **Supporting external projects**

This year many institutions have had challenges in obtaining ethical approval for face-to-face studies. Instead, they have changed to non-contact studies, mainly surveys and mainly involving families rather than children. Many researchers have approached The Children's Trust, as a charity, to help recruit participants through the Brain Injury Hub and social media channels. The research lead has screened these projects for alignment with our clinical services and also monitored the governance of the projects. Not all projects have been supported, for example if they haven't been able to demonstrate ethical approval or if the topic is not a priority in clinical or educational services e.g. audiology community services.

### **External roles and memberships**

The Research lead is in the final year of her role on the steering committee of a research project funded by Elizabeth Casson Trust to build occupational therapy research capacity. She is also in the final year of her position on the General Management Committee of European Academy of Childhood Disability. Both of these roles have been extremely valuable in fostering relationships within the children's disability community. The Research music therapist continues the role of Research Chair of Independent Neurorehabilitation Providers Alliance. The Research and Consultant speech and language therapists continue their role as Research Champions, Royal

College of Speech and Language Therapists. An occupational therapist and Research physiotherapist) continue to be members of research steering committees.

Research lead continues as the co-chair of the Royal College of Occupational Therapists national guideline development group. The topic is Play and Occupational Therapy. The Research lead and Therapy leads continue to be part of the national paediatric occupational therapy community of practice (Mind The Gap EBP). This group is actively promoting the translation of research into clinical and educational practice.

The psychosocial lead continues to be a member of National Acquired Brain Injury in Learning and Education Syndicate (NABLES) steering group. This year the group has launched an information programme to support education of children and young people returning to school with ABI.

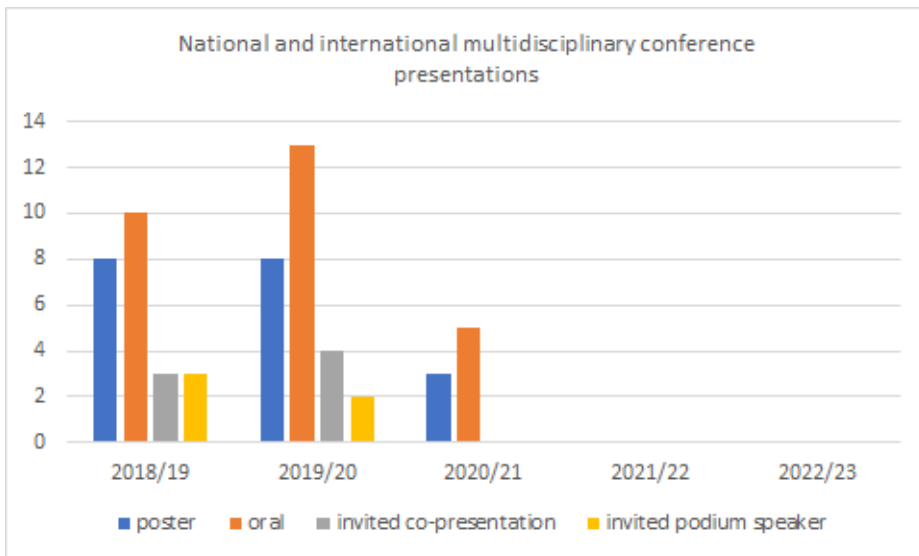
All the researchers in the team regularly review manuscripts for national and international peer review journals and screen abstracts for conference programmes.

### Publications and presentations

This year we have had **seven** peer reviewed publications and **five** book chapters (see publication list at end of report). **Five** manuscripts have been submitted and authors are responding to reviewers' comments. A further seven manuscripts are in development and Kathy Davis continues to support the writing programme at The Children's Trust.

COVID-19 pandemic has continued to interrupt the 2020/21 conference programme. Some conferences from 2020 are yet to take place. The Children's Trust was well represented at key national and international multidisciplinary conferences - British Academy of Childhood Disability, European Academy of Childhood Disability, Assistive Technology Industry Association (See figure below for annual metrics). Two members of the medical team presented an epilepsy study with Dr Darah Aylett and are preparing a manuscript for publication.

Research, clinical and medical colleagues have presented on The Children's Trust conference and webinar programme. Clinical and education colleagues have presented virtually at their professional conferences (occupational therapy, music therapy, psychology).



### Funding and awards

The Audit and research administrator was awarded Clinical Audit Professional of the year award 2020 by Healthcare Quality Improvement Partnership.

It is Year 2 of the Wellcome grant. The project title is 'Public involvement in childhood neurodisability research: moving up a gear.' The fund is £75,000 over 3 years. The MuSICCA team have secured funding in the USA (Professor Wendy Magee) and will begin data collection. There have been unsuccessful in 3 grant applications this year. There are two current applications in process (Wellcome and Sparks/GOSH). Grant applications are being supported by academic partners at Oxford Brookes University and Anglia Ruskin University.

Research lead continues to bring additional income from external supervision. The supervisee has benefitted from clinical and academic support. She has recently submitted an article to OTNews and has an interview for the NIHR pre-Masters bridging programme this week.

Therapists from The Children's Trust School were awarded MacKeith Best Poster Presentation prize at British Academy of Childhood Disability.

### Fellowships, leadership and academic training

Seven members of nursing and allied health professional teams have been engaged in post-graduate training this year. Some courses have been interrupted but are now progressing well again (nurse educator and BICS MTC lead). Two speech & language therapists are studying at PhD level. One nurse and two occupational therapists continue with their MSc studies. The research team offer support and mentorship as required.

Dr Lorna Wales,

Research lead, 28 June 2021



## Publications 2019-20

### Book chapters

Liz Roberts has contributed three book chapters which are currently in press:

- Roberts, E., Brett, R., & Murphy, T. (in press). A brave new world: Paediatric Tele-Neuropsychology. In R. Booth & T. Murphy (Eds.), *Paediatric neuropsychology within the multidisciplinary context*. London: UCL.
- Farran, E., Gilligan, K., & Roberts, E. (in press). Visuospatial processing. In R. Booth & T. Murphy (Eds.), *Paediatric neuropsychology within the multidisciplinary context*. London: UCL.
- Santariano, S., & Roberts, E. (in press). A neuropsychological lens on the impact of lockdown on children and young people. In C. Arnold & B Davis (eds.), *Children and a pandemic*. London: Karnac.

Jonathan Pool and Claire Woods have contributed a chapter 'Music therapy in paediatric neurorehabilitation' to the Oxford Handbook of Early Childhood Music Learning and Development (OHECMLD) which is due to be published soon.

'Supporting children and young people with atypical communication needs' – book chapter (jointly written with Dr M Viviers, SLT, ELCH) for a handbook for healthcare professionals supporting people with communication needs – in progress (likely print Dec 2021 with Routledge Press)

### Journals

#### Submitted

Wales L, Grove T, Hamilton C, Forsyth R Experiences of capturing rehabilitation outcomes for children and young people with severe Acquired Brain Injury. (*Disability and Rehabilitation journal*)

Forsyth, Rob; Hamilton, Colin; Ingram, Matthew; Kelly, Gemma; Grove, Tim; Wales, Lorna; Gilthorpe, Mark. Demonstration of functional rehabilitation treatment effects in children and young people after severe Acquired Brain Injury. (*Developmental Neurorehabilitation journal*)

Wilkinson D, Hamilton C, Edwards L Using Therapy Outcome Measures to identify the Speech and language therapy needs of children and young people with severe acquired brain injury (*International Journal of Therapy and Rehabilitation*)

Viviers, Asir, Edwards et al 'An enhanced rapid review of the applicability of ultrasound in the assessment of sucking, swallowing and laryngeal function in the paediatric population' (*International Journal of Language and Communication*)

Kelly G, Perkins A, Owens L, Wales L "It was good... A bit disappointing that I can't really use a normal bike": The experiences of young people returning to physical based leisure activities after a severe acquired brain injury (*Disability and Rehabilitation*)

## Published

Pool JW, Siegert RJ, Taylor S, *et al* (2020). Evaluating the validity, reliability and clinical utility of the Music therapy Sensory Instrument for Cognition, Consciousness and Awareness (MuSICCA): protocol of a validation study. *BMJ Open* doi: 10.1136/bmjopen-2020-039713

Costello G and Bennett E (2020) From politics to the playground: Putting childhood-acquired brain injury on the timetable. *Nasen Connect* Available at <https://ukabif.org.uk/news/521464/From-politics-to-the-playground-Putting-childhood-acquired-brain-injury-on-the-timetable-.htm>

Burrough M, Beanlands C and Sugarhood P (2020) Experiences of Using Pathways and Resources for Engagement and Participation (PREP) Intervention for Children with Acquired Brain Injury: A Knowledge Translation Study *Int J Environ Res Public Health*; 17(23):8736. doi: [10.3390/ijerph17238736](https://doi.org/10.3390/ijerph17238736)

Wales L, Davis K, Kelly G, Lynott H (2021). Long Term Participation Outcomes for Severe Acquired Brain Injury in Childhood - An Expanded Scoping Review. *Dev Neurorehabil*. Feb 20:1-9. doi: 10.1080/17518423.2021.1886191.

Palanivel V and Burrough M (2021) Acquired brain injury in children, and their rehabilitation: where we are now? *Paediatrics and Child health* DOI:<https://doi.org/10.1016/j.paed.2021.02.001>

Buckeridge K, Clarke C and Sellers D (2020) Adolescents' experiences of communication following acquired brain injury. *International Journal of Language & Communication Disorders*, 55: 97-109. <https://doi.org/10.1111/1460-6984.12506>

Baker FA, Pool J, Johansson K *et al* (2021) Strategies for Recruiting People With Dementia to Music Therapy Studies: Systematic Review, *Journal of Music Therapy* <https://doi.org/10.1093/jmt/thab010>

