

The Children's Trust Research Governance Committee

Progress Report June 2020

Introduction

The Children's Trust Research Governance Committee is delighted to welcome new members this year. Dr Ignacio Agrimbau joins as an educationalist.

The Children's Trust launched a new 5-year strategy this year "Hope and Ambition". The launch of this new organisational strategy prompted a review of the 2018-2023 research strategy. This Research Governance Committee Report will report progress of the existing research strategy. A new draft research strategy will be circulated to the Research Governance Committee in the coming months.

The management of the Research Team has changed in recent months following the resignation of David Knivett, Clinical Education Team and Research Manager. Dr Lorna Wales, Research Professional Lead has reported directly to Jayne Cooper, Director for Clinical Services, in the short-term pending a review.

The research team appointed Katherine Buckeridge, Speech & Language Therapist for a 1-year contract as a clinical academic. Katherine is registered for PhD at University of Kent. A short secondment opportunity to the research team was taken by Saphia Abou-Amer, music therapist from The Children's Trust School. Dr Jonathan Pool has taken up a part-time academic position at Anglia Ruskin University, Cambridge. He no longer has clinical duties at The Children's Trust. He maintains a 1 day/week position in the research team as a clinical academic.

The Brain Injury Community Service (BICS) appointed Katy Rodgers as a research link. She has attended research group meetings remotely over the year and co-ordinated a monthly BICS research working party.

The research group has met in person 5 times this year. On the months when it was not possible to meet, a newsletter was circulated to the group (see attachments for minutes and newsletters). Specific emails were sent when direct decisions and opinions were required. COVID-19 has interrupted recent meeting scheduling. Remote meetings via video call will start from July 2020.

There was an Annual Research Day in February 2020. Tim Grove (Quality Lead) will arrange a Quality Day later in the year.

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

This year's research programme has included 37 projects of which 16 include an external national or international collaboration (see separate document).

The recent COVID-19 pandemic has had an impact on the way The Children's Trust delivers services to children and young people with brain injury and neurodisability. The research team carried out a survey of clinical staff to gauge the possibility of a research project. Staff shared their experiences of changes to placement conditions, working practices and changes to interventions. A number of small projects and reflections will be written for a range of publications. Some rehabilitation outcome data will be evaluated and nursing and care roles will be explored.

MuSICCA is an international, multicentre project (validation of assessment for children and youth with Disorders of Consciousness) which now has ethical approval to commence data collection. Funding applications continue and in the meantime data collection is starting at The Children's Trust.

AmBI is a long term follow up study of children and young people from our residential rehabilitation service. Ethical approval is pending and Lorna Wales, Kathy Davis and Gemma Kelly will start data collection remotely in the coming months. Further funding applications will be made to continue the project once we have reached the limit of the current staffing resource in the research team. Gemma Kelly has carried out a qualitative study of children and young people's experience of returning to Physical Activity following an Acquired Brain Injury (ABI). This project has been a collaborative venture between therapy, research, psychology and families and a manuscript is prepared for publication.

We continue to collect, develop and share rehabilitation outcome data from residential rehabilitation and BICS. We have a number of projects developing excellence in our services. The research team has led the development of data collection models that are shared widely amongst external collaborators and commissioners. Dr Rob Forsyth continues to partner on this work and design multicentre research in rehabilitation outcomes.

Brain Injury Community Service – Outcome measure evaluation

The Children's Trust collaborated with Holland Bloorview Kids Rehabilitation Hospital, Canada for a validation study of a new family measure – Family Needs Questionnaire-Paediatric version (FNQ-P). The residential and community rehabilitation services at The Children's Trust have introduced the use of this tool in their service. BICS collected data routinely for a period of time, they had a teaching session and then gathered and analysed all of the data they had collected. They evaluated the use of the tool for their service and reported the trends across the group of 187 parents. Two of the team have written an abstract which has been accepted to present at international conference. BICS is now in a strong position to make a clinical decision about the place of this measure in their service, and to share this experience with colleagues.

The Children's Trust School has managed some detailed service development and evaluation projects this year which influence excellence and best practice (participation, TASELS). These projects bring a diverse richness to the research portfolio and some of these projects will develop into formal research ideas. The messages from these projects are shared at conference and are well received by the academic community (see Presentations).

Dr Rishwa is currently leading the Medical Team (both Doctors and Support staff) on nine Quality Improvement (QI) projects. All QI have set objectives and the team meet regularly to discuss/ monitor progress. Tim Grove (Quality Lead) and Lorna Wales will develop processes in the coming year to formalise QI projects and present a Quality portfolio to the committee in 2021.

We continued our research relationship with Colin Hamilton, previous fixed term researcher. Colin was able to support an application to NHS Digital, and The Children's Trust acquired the most current incidence data for Acquired Brain Injury across all ages and regions in England. In the coming months we will use this dataset in presentations, for business planning (particularly for BICS and new strategic ambitions to grow services) and helping to understand the national need for this group of children and young people.

We continue to integrate technology developments into our clinical services. A site-wide technology working group has been formed to review projects and collaborations with external partners. We will continue to consider research opportunities alongside the clinical developments.

We have shared datasets of outcome data with two MSc preregistration students at Brunel University and UCL, London. These projects are validating measures for children and young people with ABI. The students will be invited to present at our Research Day next year, provide information for our webpages, and work towards a peer reviewed publication.

Lorna Wales has attended clinical team development days to discuss the contribution of individuals and teams to the research portfolio. The teams have made collaborative decisions about the research capacity in their teams and prioritising developments over the coming years, including writing for publication, writing evidence summaries, data collection and original research ideas.

Publications and presentations

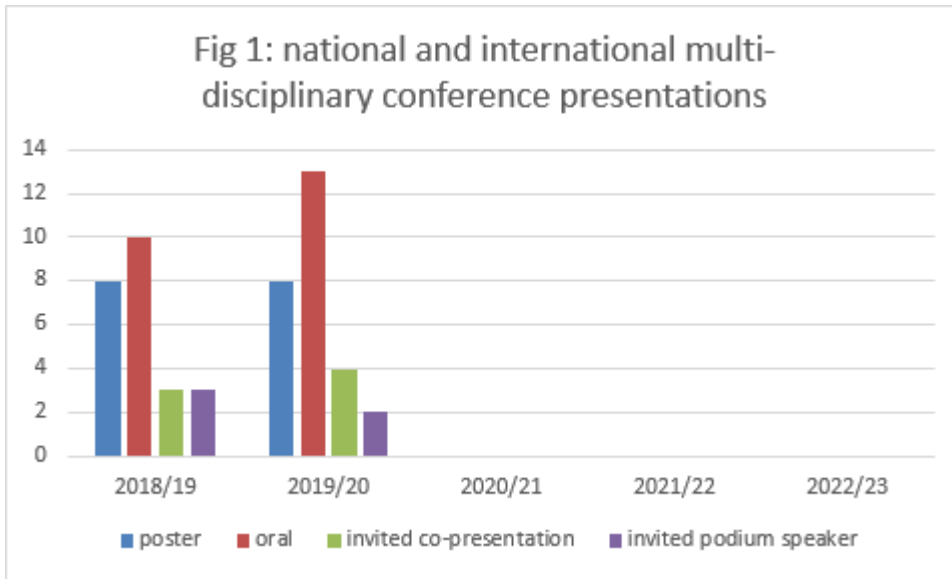
The research team continue to support the clinical team to have a presence at key multidisciplinary national and international conferences. In the past year we are particularly pleased to have been invited to co-present with international academic partners at International Alliance of Academies of Childhood Disability (Melanie Burrough) and International Paediatric Brain Injury Society (Lorna Wales, Gemma Costello). Alison Perkins (psychologist) had an abstract accepted to present at the CBIT conference.

COVID-19 pandemic has interrupted the 2020 conference programme. Many conferences have been postponed or cancelled. We have had our work *accepted* at 13 multidisciplinary conferences (See figure below for year 2 metrics). Of the conference presentations that we have delivered this year, we have received three awards for best poster (Lorna Wales, Louise Edwards, Natasha Watson).

Having presented the UKROC report to our NHS Commissioning partner, we were encouraged to submit our outcomes work to the South East Thames Network meeting and invited to deliver a podium presentation for the UKROC outcomes project. We were also accepted to have a poster presentation of tracheostomy outcomes and were awarded a poster prize at the event.

Lorna Wales was invited to be part of the organising committee of *Effective interventions for the rehabilitation of survivors of brain tumours and other brain injuries acquired in childhood* conference. Lorna and Debbie Levy, Surrey Child Health partner, presented together on a model of delivering shared case work in ABI rehabilitation.

This year we have published **four** peer reviewed publications and **seven** book chapters (see publication list at end of report). A further six manuscripts are in preparation, and three are responding to reviewers' comments. Kathy Davis has a leading role supporting writing for publication at The Children's Trust. Her advanced academic writing skills are valued on many projects within the organisation.



Collaboration

The Children’s Trust has maintained some key collaborations in this past year. Through our growing relationships we were able to extend an invitation to Professor Vicky Anderson and Associate Professor Stacy Suskauer to headline at The Children’s Trust conference, 2019. Professor Anderson came to the Children’s Trust for an extended period and in addition to delivering lunchtime lectures, she also attended team and project meetings.

Melanie Burrough continues to develop an international collaboration with Associate Professor Dana Anaby, McGill University, Canada. Mel co-presented her work on Pathways and Resources for Engagement and Participation (PREP) at an international conference in USA. She is co-authoring a manuscript and is contributing to the development of an online training resource.

There has been a growing interest from clinicians with an academic/research interest in other children’s services within the South East to work more closely together. Some individuals were invited to a networking meeting on the recent Research Day (Chailey, Treloars, Young Epilepsy, Valence School). It is encouraging that clinical colleagues perceive The Children’s Trust positively in this networking role.

Epilepsy

We continued to develop our research relationship with Young Epilepsy this year with a visit to the site in Lingfield. In December, The Children's Trust hosted an Epilepsy masterclass that was attended by a range of clinical professionals. Lisa O'Brien, Head of Health at Young Epilepsy updated the teams on the epilepsy classifications and current topics in epilepsy.

Kathy Davis and Lorna Wales attended the 10th Epilepsy Research Retreat attended by eminent international researchers at Amy Muggeridge's invitation.

Dr Nirmal and Dr Vargas continue a service evaluation project of epilepsy, reviewing case notes to consider the role of EEG in diagnosis and treatment of complex disability. They collaborate with Dr Sarah Aylett, Great Ormond Street Hospital.

External roles and memberships

Lorna Wales and Sammy Randall (occupational therapists) have continued on the steering committee for 2 external research projects. Sammy's role will finish with PenCRU project, but she remains on the Professional Advisory Committee of ERIC charity. Through the link with Oxford Brookes University Lorna has been able to explore further academic opportunities and networking with OT doctoral and post-doctoral researchers.

Lorna has been selected to join the Guidance Development Group with Royal College of Occupational Therapists, and has been voted as vice-chair. The topic is Play and Occupational Therapy. Lorna Wales, Sharon Tuppeny and Melanie Burrough are all part of a shared initiative amongst children's occupational therapists to form a network and promote the uptake of research evidence into practice. It is a national group of clinical, educational and research occupational therapists (#MindTheGap).

Jonathan Pool has accepted a role of Research Chair of Independent Neurorehabilitation Providers Alliance. Lorna Wales continues her as a member of the General Management Committee (newsletter editor), European Academy of Childhood Disability and committee member of International Alliance of the Academies of Childhood Disability. Gemma Kelly continues as a member of Physiotherapy Research Society who hosted a successful study day in this last year.

Louise Edwards and Katherine Buckeridge are both research champions for the Royal College of Speech and Language Therapists.

Funding

This year the research team was successful in securing a research grant from The Wellcome Trust. The project title is 'Public involvement in childhood neurodisability research: moving up a gear.' The fund is £75,000 over 3 years.

Dr Rob Forsyth is resubmitting an NIHR grant application to explore rehabilitation outcomes for children and young people with ABI. Lorna Wales is a co-applicant with a small percentage of paid time on the project. The Children's Trust will receive payment per child in order to carry out the outcome measures.

Lorna Wales is submitting a grant application with the therapy team to the British Scoliosis Research Foundation. The study will investigate 'Rigid thoraco-lumbo-sacral spinal orthoses (bracing) for children and young people with severe neurodisability'.

Melanie Burrough was successful in winning the Logo competition for the new International Alliance of the Academies of Childhood Disability (IAACD). The prize was a travel award to attend the 2nd IAACD conference in USA.

Lorna Wales has secured additional income from external teaching and external supervision.

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

Part of the technique for knowledge translation at The Children's Trust is the production of evidence summaries. During the recent COVID-19 pandemic there are a number of clinical staff, students/trainees working from home for health reasons. There has been an opportunity for some of those staff to increase the production of Evidence Summaries. Some have taken the opportunity to access support from our librarian. Remote discussions have been taking place about the levels of clinical evidence they have found, and they have been comparing different interventions for our children and young people. This project has increased their research skills and will improve the quality and excellence of services in the future.

School therapy, rehabilitation therapy, psychosocial and BICS teams have all worked with the research team to plan the development of evidence summaries. The next step is to manage the implementation of the recommendations into clinical practice. One of the Working From Home team recently carried out an audit which included the use of intervention language in the treatment plans and clinical notes. This report will be used to measure the implementation of evidence into practice and reflects a positive change since last year's report. The findings having informed part of the electronic clinical notes project within the organisation.

The oral health project is a good example of embedding quality and excellence into our clinical services. Kathy Davis supports this project team who have shown improvement in care through the use of audit cycles. They have written and updated an oral health policy and Standard Operating Procedure (SOP). They have sought external collaboration and expertise from The Royal Hospital, Putney. Oral health is on the national child health agenda and The Children's Trust can demonstrate an ability to adapt policy to local need for this complex group of young people in our care.

Family involvement in accessing and using research evidence is part of the PPI funded research project. We are recruiting parent volunteers to work with the research team to co-produce accessible resources and maximise utility of our library facility.

Physiotherapy team – gait pathway

The rehabilitation physiotherapy team is involved in this project. Each team member partners up and has been allocated an intervention to read around. They produce an Evidence Summary. The team are working towards a decision-making tool that will guide evidence-based practice and collaboration with shared decision-making with children, young people and families.

Team clinical meetings are reported to be more concise. The language used to handover and discuss physiotherapy interventions is more targeted and clearer. For example J's goal is to walk on his own around his room, he is using treadmill training and dynamic balance training. He responds best listening to his music on the treadmill in order to reach the 20 minutes he is aiming for, and enjoys playing football games for his balance.

During Saphia's secondment to the research team she was particularly interested to learn the literature in order to inform the emerging service developments for children and young people in The Children's Trust School with a Disorder of Consciousness. She updated her skills in searching and appraising literature and was able to establish key learning for the wider educational and clinical staff groups within The Children's Trust School.

This year's Research Day was held in February and was well attended by a range of disciplines. The keynote speaker was Dr Benita Powrie who shared the findings from her PhD titled "The meaning of leisure to children and young people with significant physical disabilities". This lecture was of interest to all clinical services. There were a mixture of oral and poster presentations and the programme was varied. COVID-19 has interrupted the feedback survey but immediate feedback on the day was positive and social media engagement was good.

Fellowships, leadership and academic training

Firstly, we celebrate with Professor Jenny Jim who has received two academic honours this year. Jenny has been awarded Honorary Associate Professor at UCL and has also been nominated for an "early career award" by the Division of Neuropsychology. Jenny's trainees continue to add robust research studies to our portfolio.

Sue Walker (educational psychologist) has successfully defended her PhD at Swansea University. Her thesis "Participation in the home, community and school following in-patient

rehabilitation for severe childhood acquired brain injury" is relevant to our clinical interventions and supports the AmBlt follow up study. We have approached Dr Walker to have some summary information for The Children's Trust website.

The Children's Trust has benefited from support of the Research Design Service at Surrey University. The team there have reviewed our research protocols and grant applications. Lorna Wales has been advised of the need to establish a formal academic position. Positive discussions with Oxford Brookes University are progressing well.

Research team members now have formal academic appointments outside of The Children's Trust. Jonathan Pool at Anglia Ruskin University and Katherine Buckeridge at University of Kent. Colin Hamilton secured a NIHR bridging fellowship and is planning to commence a PhD programme next year. Lorna Wales will be on his supervision team.

Alison Fletcher (BICS) has secured a place on an MSc programme starting Autumn 2020. Helle Mills (OT, placements team) is progressing an NIHR application on the clinical academic pathway. Sammy Randall (OT) is progressing an application for MSc starting Autumn 2020.

We have two nurses on post-graduate courses. Carla Chadwick (Clinical Education Team) is completing a Post-Graduate Certificate (PGCert) in Teaching. It is currently on hold and she will continue in the Autumn. Carla hopes to progress to a Post Graduate Diploma. Michael Humphrey-Jones is completing year 1 of MSc in Neurosciences. Kathy Davis supports and encourages nurses to continue post-graduate education.

Teaching

The research and clinical teams continue to be invited to speak at external training events and seminars. Case managers, professional and academic colleagues all make approaches and The Children's Trust is well represented at nationally and internationally at study days, seminars, conferences and web-based teaching. Clinicians from the therapy and psychosocial teams are invited to deliver guest lectures on undergraduate and postgraduate training courses. Jonathan Pool recently delivered his first public lecture at Anglia Ruskin University.

Louise Edwards (S< consultant) has been contributing to international web-based learning and building a strong social media profile this year with researchers and clinical experts. Following Sammy Randall's networking, she is presenting a small workshop seminar at ERICs next conference on the topic of therapeutic approaches to toileting. Lorna Wales is presenting on The Children's Trust's current webinar series following the publication of the rehabilitation outcomes report.

Within the organisation, Helen Lynott has been engaging many groups of staff in tutorials to make more use of the library. These sessions are included on the induction programme. Helen has delivered teaching to clinical teams and to individuals. Staff report positively about this support to become more independent in their ability to search and find evidence for their practice.

Kathy Davis supports the learning and development programme for the Preceptorship nurses at The Children's Trust. Kathy works with the Clinical Education Team to develop a programme to meet the learners needs. The teaching is interactive with six preceptorship nurses, some of whom have been trained to degree level, learning/reviewing how to critique literature, present findings, carry out audits and projects.

Dr Lorna Wales,

Research Professional lead

29 June 2020

Publications 2019-20

Book chapters

Psychological Therapy for Paediatric Acquired Brain Injury The book is Edited by Jenny Jim and Esther Cole with chapters by Jenny, Alison Perkins, Laura Carroll, Elizabeth Roberts and Gemma Costello

Alison Perkins has had a chapter printed in Meredith, K. H., & Yeates, G. N. (Eds.). (2019). *Psychotherapy and Aphasia: Interventions for Emotional Wellbeing and Relationships*. Routledge.

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).

Journals

Wales, L., Dunford, C., & Davis, K. (2020). Following severe childhood stroke, specialised residential rehabilitation improves self-care independence but there are ongoing needs at discharge. *British Journal of Occupational Therapy*. <https://doi.org/10.1177/0308022619894870>

Wilkinson D, Bate C, Viera M, Stothard C, Corkett R, Mills H (2020) Augmentative and Alternative Communication provision pathway: single item activation to linking ideas and navigating. *Communication Matters*

Gan C, Van'T Hooft I, Brookes N, Prasauskiene A, Wales L, Wright V (2020) First Stage International Validation of the Pediatric Family Needs Questionnaire (FNQ-P) *Brain Injury* (editors final check)

Kelly G, Moys R, Burrough M, Hyde S, Wales L (2020) Rehabilitation in Practice: Improving Delivery of Upper Limb Rehabilitation for Children and Young People with Acquired Brain Injuries through the Development and Implementation of a Clinical Pathway. *Disability and Rehabilitation* early online

Pool, J (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* (accepted)

