Government of **Western Australia**
Child and Adolescent Health Service

Perth Children's Hospital

Kids Rehab WA Research

July 2021- June 2023
Biennial Report

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

THE UNIVERSITY OF WESTERN AUSTRALIA

Curtin University

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Kids Rehab WA

Kids Rehab WA is a state-wide, integrated tertiary clinical, research, education and training unit at Perth Children's Hospital, Western Australia. Kids Rehab WA offers inter-disciplinary services to children and adolescents in Western Australia with acquired or congenital neurological impairments.

Our Vision

Enabling healthy kids and healthy communities through excellence in paediatric rehabilitation clinical care, education and research.

Our Mission

To be the state-wide centre of excellence for paediatric rehabilitation and integrated research in Western Australia and, to provide the best healthcare and disability support, informed by consumer involvement, well supported staff, research and community collaboration.

Our Goal

Kids Rehab WA will improve participation and health outcomes for children and families requiring paediatric rehabilitation services.

Our Priorities

Children with complex neurodevelopmental conditions ***have their needs met and supported*** by Kids Rehab WA service streams

Minimising the impact of Social Determinants of Health on access and outcomes

Early detection and intervention

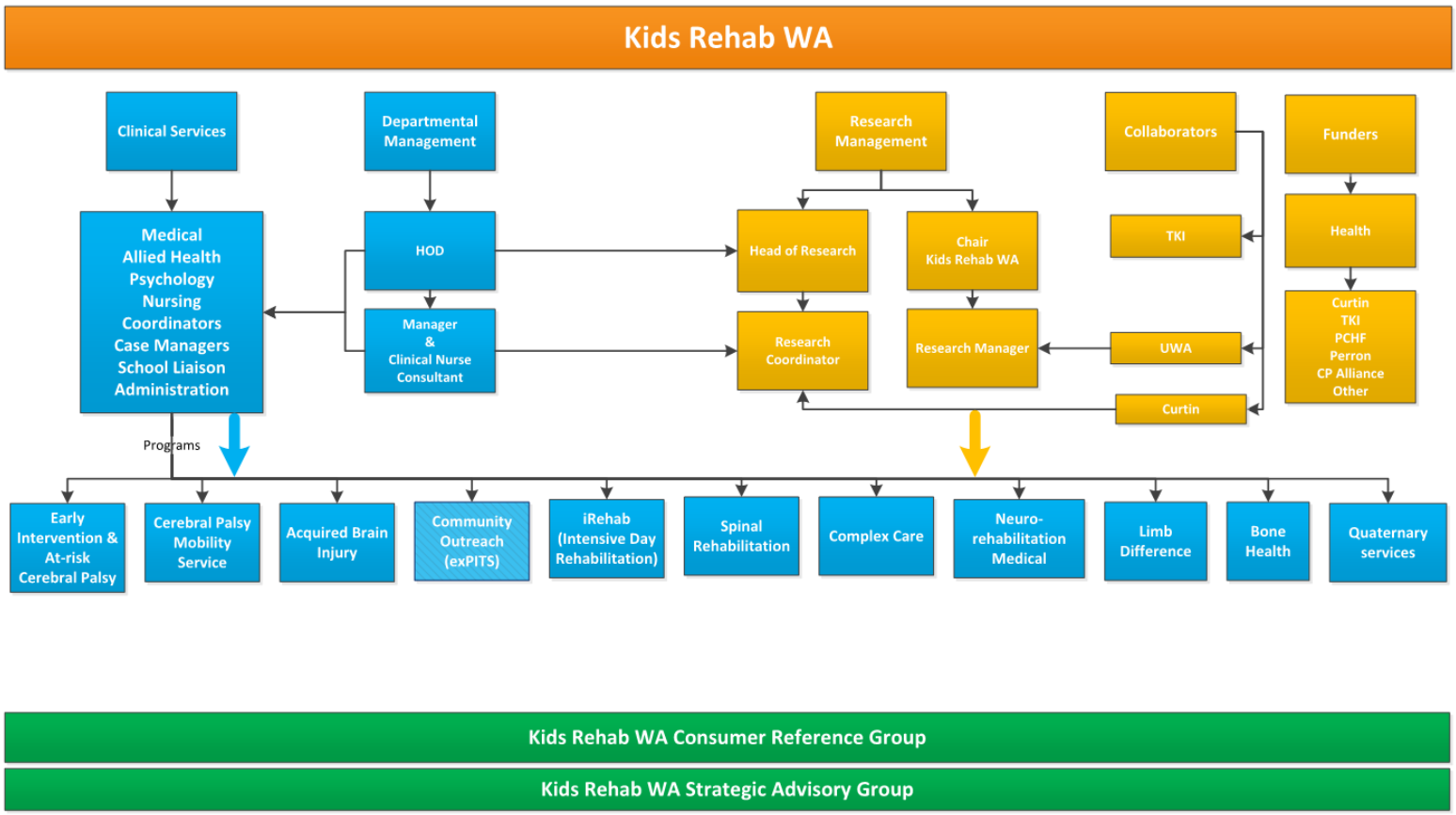
Sustainable clinically integrated research program

Ethics and Governance

Kids Rehab WA research is conducted in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007) and the Australian Code for the Responsible Conduct of Research* (2018*);* in compliance with the WA Health Research Governance Framework.

Integrated Clinical Programs

As part of the Child and Adolescent Health Service (CAHS), Kids Rehab WA has a clinically integrated research unit with an established consumer reference group and clinical database. This ensures that we support the basic principles of the current CAHS research plan; and that research as a core aspect of the CAHS mission is embedded into practice. The Kids Rehab WA Research Program conducts clinical research along the broad continuum of paediatric rehabilitation care. Kids Rehab WA provides the sole state-wide rehabilitation service to Western Australian children and has established comprehensive follow up for patients and links with the community, providing a unique opportunity for both research and knowledge translation.



Kids Rehab WA Consumer Reference Group

The Kids Rehab WA Consumer Reference Group was established in 2017 to inform the development of a sub-acute care unit as part of Kids Rehab WA at Perth Children's Hospital (PCH). The Consumer Reference Group is made up of young people, and parents of children, who have accessed (or are still accessing) Kids Rehab WA services.

After their valuable contribution to the development of the sub-acute care unit, the Consumer Reference Group has evolved and continues to meet regularly throughout the year. Their role is to:

- Act as a liaison between consumers, community organisations and Kids Rehab WA
- Advocate to the Kids Rehab WA on behalf of consumers and the community
- Direct and guide research, service development and the implementation and evaluation of research evidence into practice

The Consumer Reference Group has contributed to priority setting for clinical services and research within Kids Rehab WA. Key Consumer Reference Group activities conducted within this reporting period include:

1. Input into and feedback on the Kids Rehab WA Department Strategic Plan
2. Input into and feedback on Accelerate WA proposal and funding application
3. Providing letters of support endorsing funding applications to Stan Perron Charitable Foundation, Perth Children's Hospital Foundation, Department of Health for research funding applications
4. Developing a broader consumer engagement strategy for Kids Rehab WA
5. Contributing to qualitative data analysis for research papers
6. Consulting on service improvement and development for Kids Rehab WA

Member Spotlight: Wendy Langford

Wendy Langford has been a member of the Kids Rehab WA Consumer Reference Group since it's inception in 2017. Before parenthood, Wendy had a full-time career as an Occupational Therapist, working first in psychiatry then in adult and aged care rehabilitation. She also gained a post graduate diploma in Health Promotion and worked briefly in that area.

After becoming a parent, Wendy worked periodically as a part time OT for a few years, before deciding to focus on caring for family and on voluntary roles. These have included membership of various boards, committees and groups in the health, disability, and education spheres, making use of both her professional background and her lived experience. Wendy describes her motivation for joining the Kids Rehab WA Consumer Reference Group below:

"I've been a carer for 22 years, having a daughter with physical and intellectual disabilities who was a "frequent flyer" at PMH/PCH until she transitioned to adult services. I joined the group because I like being able to put my lived experience as a parent carer to good use, in the hope that it can help improve the experience of families following in our path."

Paediatric Rehabilitation Information System (PRIS)

Kids Rehab WA has an established and comprehensive clinical database for children receiving paediatric rehabilitation services – the Paediatric Rehabilitation Information System (PRIS). PRIS records clinical assessments and tertiary interventions for children in Kids Rehab WA clinical programs and research projects. In 2013, the initial Paediatric Rehabilitation database, established in 2003 with data retrospective to 1995, was integrated into the upgraded Paediatric Rehabilitation Information System (PRIS). This upgrade allowed connection between PRIS and the WA Health web-based Patient Administration System (WebPAS).

In March 2021, a further upgrade to PRIS was completed to incorporate clinical data collected during standard clinical care for children 0 – 2 years of age attending the Early Intervention service. The latest upgrade adds to the capacity to capture comprehensive clinical data across a child's developmental trajectory while they are accessing Kids Rehab WA services. This information helps us to improve services, for example, by monitoring and evaluating the implementation of best practice guidelines for early detection and early intervention for babies at risk of cerebral palsy.

The upgrades to PRIS and its connection with WebPAS means that PRIS now provides: (i) data on clinical services; (ii) accurate and timely reporting of service events; (iii) waitlist information; (iv) key performance indicators for clinical programs; and (v) capture, safe storage and retrieval of clinical information. PRIS is utilised to periodically export data to national clinical registers and benchmarking committees including: Australasian Paediatric Rehabilitation Outcomes Centre (APROC), Western Australian Register of Developmental Anomalies, National Selective Dorsal Rhizotomy Register and National Intrathecal Baclofen Register.

Data generated from PRIS have also contributed to clinical and service development for Kids Rehab WA through the development of research questions and quality improvement activities via the Governance, Evidence, Knowledge, Outcomes (GEKO) program.

Following ethics and governance approval, PRIS has enabled the identification of relevant patient cohorts for local, national and international clinical research studies, including NHMRC funded trials such as HABIT-ILE (APP1144846) and Participate-CP (APP1140756). Data collated in PRIS has facilitated the successful completion of seven Royal Australasian College of Physicians (RACP) trainee projects in the last three years, with one currently accepted for publication, two under preparation and three accepted for presentations at international conferences. Ten applications to PRIS have been led by Kids Rehab WA Allied Health staff, four have informed the clinical audit of programs and quality control and a further four have facilitated patient enrolment in other department-led trials. A summary of the number of PRIS data requests per annum, since its inception, can be found in Figure 1.

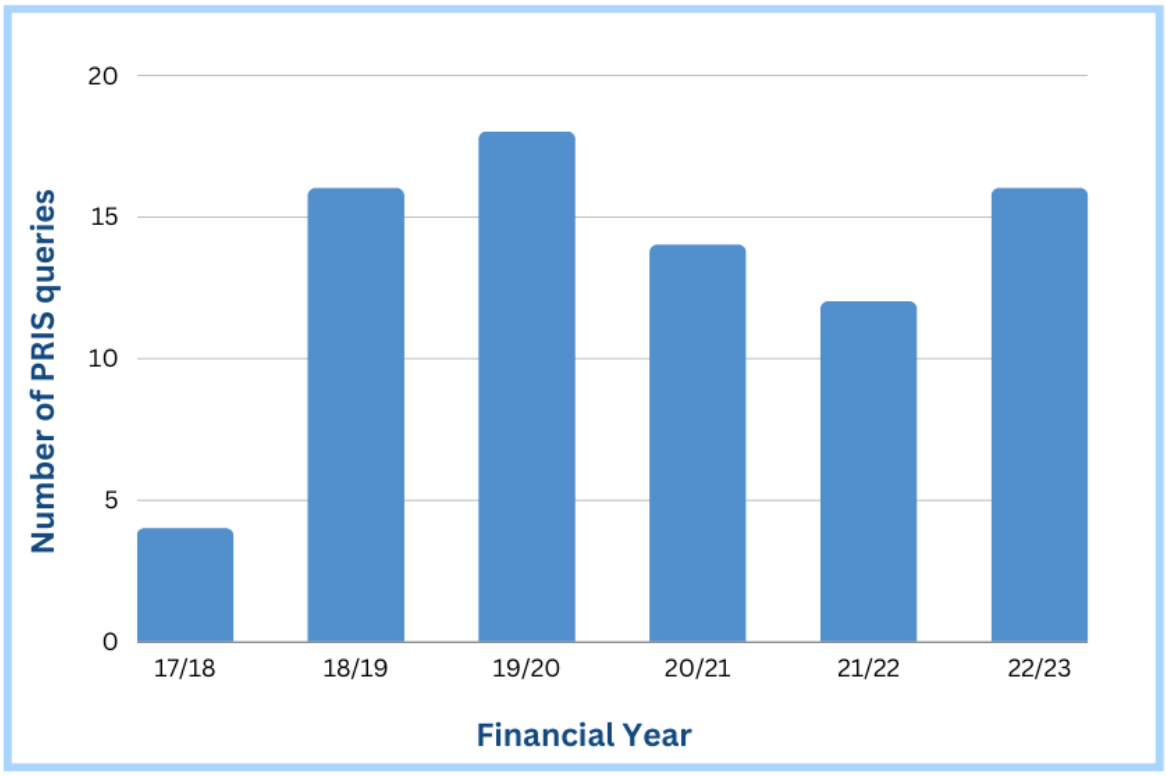


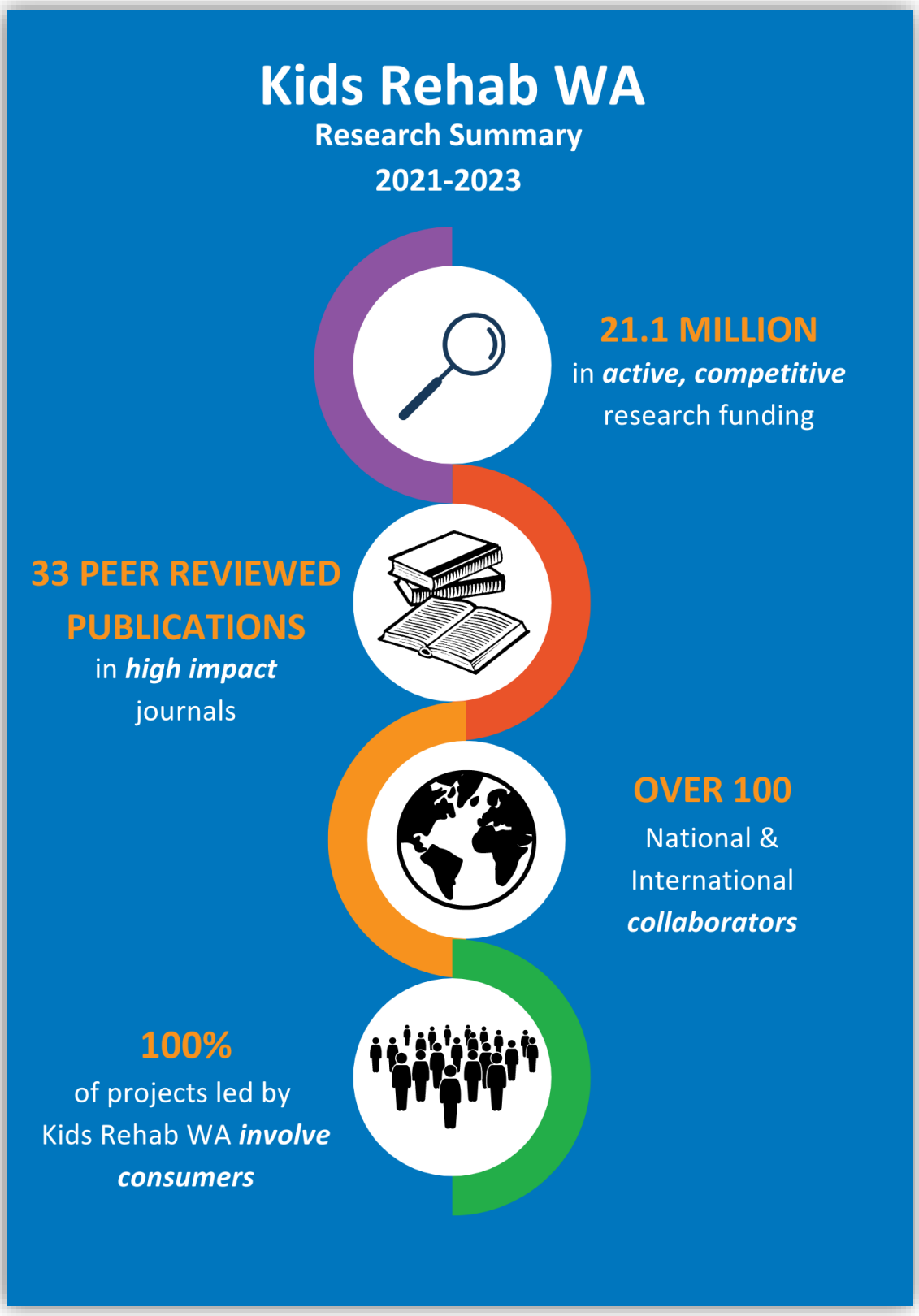
Figure 1. Data requests for PRIS per financial year

Governance, Evidence, Knowledge, Outcomes (GEKO)

During the 21/22 and 22/23 financial years, Kids Rehab WA clinical teams have remained committed to quality improvement (QI) projects. The GEKO process has changed, with projects now approved and monitored by the CAHS safety, quality and performance QI committee. Work continues for 8 existing QI projects, with four additional projects initiated through the new process during this financial year.

The aims of Kids Rehab WA QI projects remain broad and encompass describing the presentation of children seen by Kids Rehab WA clinicians; the quality and efficiency of services provided; and informed use of outcome measures and interventions. The QI projects have mainly consisted of audits, surveys and literature reviews. The information and recommendations from each QI project are used to inform future QI projects and spark ideas for Kids Rehab WA to further investigate.

Research Summary



Telethon Kids Institute

Kids Rehab WA research team

Collaboration with Telethon Kids Institute (TKI) and universities provides a unique opportunity to embed world class child health research and infrastructure throughout the health service.

Telethon Kids Institute offers honorary researcher appointments to individuals not employed by the institute, which benefit both the institute and the appointee by; promoting collaboration, facilitating the exchange and sharing of knowledge, invigorating and promoting the intellectual culture, scientific reputation and collaborative networks of the institute, and recognising the contribution of researchers to the Institute.

Telethon Kids Institute has four research themes: Aboriginal Health, Brain and Behavior, Chronic and Severe Diseases and Early Environment. Each theme supports multiple research programs and teams. Since 2021, Kids Rehab WA Research has been a research team in the Diabetes, Metabolism and Clinical Sciences Research Program (led by Professor Jane Valentine), within the Chronic & Severe Diseases Theme.

Current team members for TKI Kids Rehab WA Research Team are:

Honorary Research Fellows (Team Leads): Professor Jane Valentine and Dr Ashleigh Thornton

Honorary Research Associates: Dr Alison Salt, Sue-Anne Davidson, Dr Katherine Langdon, Dr Simon Garbellini, Dr Johnson Moyle Dr Dayna Pool, Dr Tiffany Grisbrook, Dr Caroline Alexander, Dr Sarah Hall, Dr Belinda McLean

Honorary Team Members: Dr Anna Gubbay, Nadine Smith, Sam Armstrong, Renae Dayman.

Operations Manager Research: Brooke Sanderson

For more information about the Telethon Kids Institute Kids Rehab WA Research Team, see the website here.

Curtin University

Collaboration with Curtin University School of Allied Health

Curtin University's School of Allied Health and Kids Rehab WA work collaboratively to facilitate and coordinate neurodevelopmental disability research and quality improvement activities that are embedded within Kids Rehab WA clinical programs. Curtin's support and financial contribution has been significant in building capacity and continuity in our research team.

Current Kids Rehab WA staff at Curtin University:

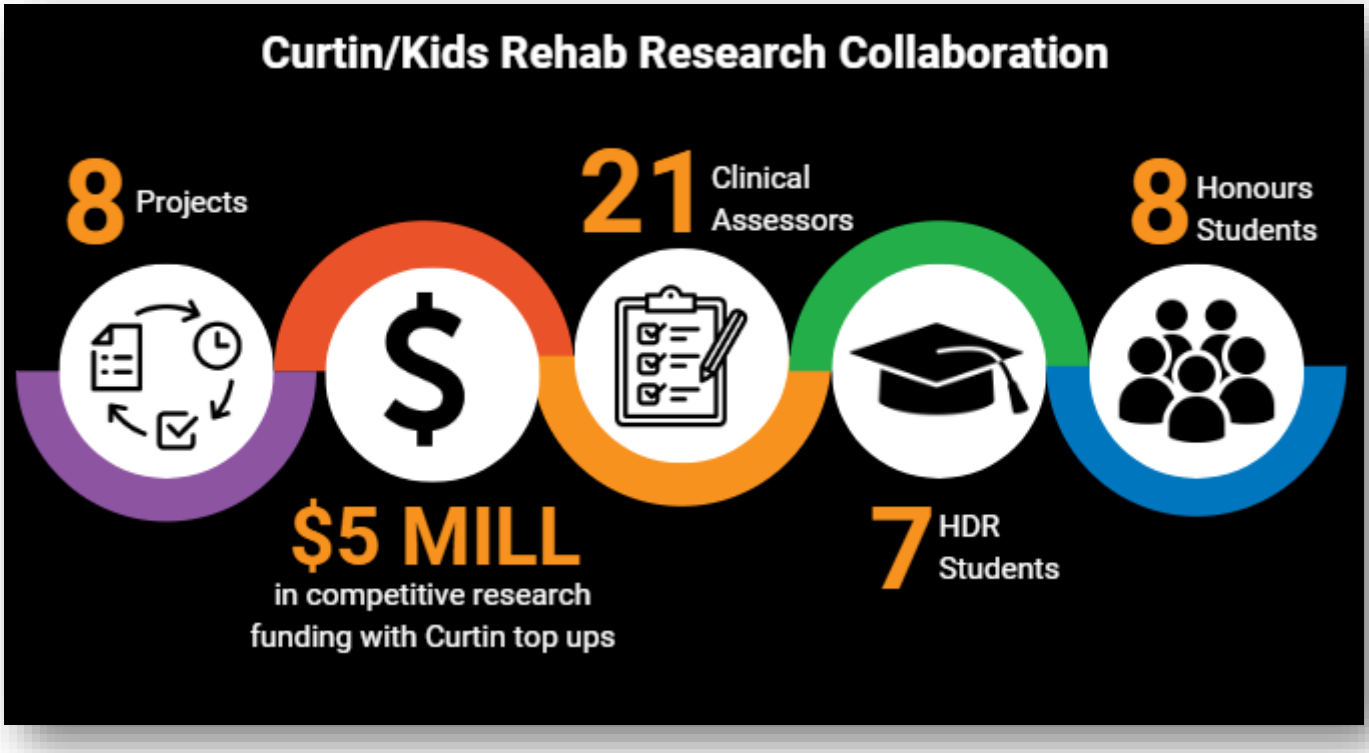
Chair of Allied Health: Professor Catherine Elliott

Research Coordinator: Dr Simon Garbellini

Post Doctoral Research Fellows: Dr Caroline Alexander and Dr Sarah Hall

Project Lead: Dr Dayna Pool

Curtin Associates: Professor Jane Valentine, Dr Ashleigh Thornton, Dr Alison Salt, Brooke Sanderson



Research Spotlight

Early Moves

Written by Dr Sarah Hall

The Early Moves project has continued throughout this reporting period (21-23). The project aims to determine whether babies' early movement patterns, called General Movements (GMs), are predictive of later cognitive delay in children. Earlier identification of children at risk would enable families to access early interventions and supports during the first 1,000 days of life, setting a strong foundation for future health and wellbeing.

Following many months of planning, the 21-22 year saw the commencement of the two-year-old developmental assessments. We now have a team of eight trained clinicians conducting these assessments at two sites - Edith Cowan University Health Centre Wanneroo and Joondalup Child Development Service - under the supervision of our Bayley-4 Program Lead, Lori Gardiner. The assessments include the Bayley-4 Scales of Infant Development, the gold standard for developmental assessment, as well as screening for autism spectrum disorder. Parents receive a report summarising their child's current development across cognitive, language, motor, socio-emotional and adaptive functioning domains. If concerns are identified, families are supported to access appropriate clinical services.

Overall, Early Moves has continued to progress well, despite the challenges with conducting face-to-face assessments during COVID-19 outbreaks in the community. The project recently celebrated three key milestones:

- Recruitment of our **2500th** baby
- Completion of our **first year** of two-year-old developmental assessments
- Completion of our **first 500** two-year-old developmental assessments

In the coming year, we are looking forward to completing recrutuiment (3000 babies), running some preliminary analyses, as well as seeking funding opportunities for further Early Moves follow-up assessments.

For more information about Early Moves, see the website here.

Research Spotlight

Australian Cerebral Palsy Musculoskeletal Health Network

Written by Dr Kate Langdon

In 2022, the Medical Research Future Fund awarded the Australian Cerebral Palsy Musculoskeletal Health Network funding. Kids Rehab WA Consultant Paediatrician, Dr Kate Langdon is a Chief Investigator on this grant, and there is great representation across Kids Rehab WA and Perth Children's Hospital more broadly. Essential support will be provided by the Kids Rehab WA's Cerebral Palsy Liaison Service which includes numerous dedicated allied health, nursing and administrative staff including the Paediatric Rehabilitation Information System staff. The cerebral palsy orthopaedic surgical staff led by Miss Kate Stannage, the spinal surgery team including Mr Siamak Seresti and their allied health and nursing support will also be involved. Dr Aris Siafarikas, paediatric endocrinologist will provide advice.

There is so much that we don't know about cerebral palsy and so often we rely on providing "best recipes" for management, by highly skilled and experienced clinicians nonetheless. However, in a perfect world all of our management discussions and algorithms would be based on clear, concise evidence-based medicine. What is needed is less reliance on the clinical experience of individual practitioners and more evidence-based certainty for families when they face difficult management decisions concerning their child.

Many medical and surgical interventions are desperately needed by children with CP because they are in pain or soon will be, or, they face a significant loss of function if preventative measures are not undertaken at the right time. Often the benefits of the interventions come at a price with a need for the child: to recover from surgery; to take medication with potential side effects; to attend appointments or be admitted to hospital. At the very least we hope that in future the risk benefit equation will reflect a uniform experience across the country so that we can be very sure that every child will have access to the right treatment and enjoy the best outcomes throughout their childhood.

We hope this research will also provide valuable data for families about the value of optimising nutrition, activity, exercise and strengthening to augment function and prevent complications, all of which can be undertaken in the community.

No other countries have established guidelines for the musculoskeletal management of CP that includes the management of the skeleton and spine. This will be a world first. No doubt along the way we will make new discoveries that will deliver new treatments for growing children with CP and insights and benefits for adults with CP as well.

This is fantastic news and gives us the opportunity to improve the wellbeing of children with CP across the nation and build an amazing platform for future clinical research.

Research Impact

Interventions to improve physical function for children and young people with cerebral palsy: international clinical practice guideline

In September 2021, International Clinical Practice Guidelines for interventions to improve physical functioning for children and young people with cerebral palsy (CP) were published by a leading group of researchers including Dr Katherine Langdon, from Kids Rehab WA.

The International Clinical Guidelines were developed through a systematic review of the currently available evidence of interventions to improve function for children and young people with CP. This guideline was developed in consultation with key stakeholders including parents, consumers, specialist clinicians and researchers from high, middle, and low-income countries.

The guideline comprises 13 recommendations for interventions to improve physical function for children and young people with CP including: four evidence-based recommendations, and nine good practice recommendations. To achieve functional goals the guidleines recommend that interventions include client-chosen goals and whole-task practice of goals. Clinicians should consider child/family preferences, age, and ability when selecting specific interventions.

Information sheets that summarise the guideline recommendations have been developed for young people and familes, and clinicians working with children with CP, and and can be foud here: [Clinical practice guidelines to improve function in cerebral palsy | Cerebral Palsy Alliance](#).

For more information on the International Clinical Guidelines you can find the paper here: [Interventions to improve physical function for children and young people with cerebral palsy: international clinical practice guideline (wiley.com)](#)


Interventions to improve function in cerebral palsy

BEST PRACTICE PRINCIPLES

Information for young people and families

The following recommendations have been developed by an international panel of clinicians to highlight best practice principles for children or young people with cerebral palsy who have functional goals. This information sheet aims to provide you with ideas based on current research. These ideas can be discussed with the clinicians who are supporting yourself or your child to achieve your goals.

SETTING GOALS THAT ARE IMPORTANT TO YOU

Intervention should always begin with clinicians asking children, young people and families what is most important to them, and setting therapy goals based around these priorities.

Functional goals are related to real-life tasks and activities (such as getting dressed and riding a bike), rather than focussing on underlying movements or impairments (such as increasing elbow range of motion).

Small, achievable goals should be set and all members of the team should have a copy of the goals so that everyone is working towards common goals.

A maximum of three goals is recommended at any one time, so that practice is achievable and children and families are not overwhelmed by trying to work on everything at one time.

PRACTICING THE WHOLE GOAL WITHIN REAL LIFE

When a child or young person has a functional goal, research tells us that the most effective way to achieve that goal is to practice the whole goal, rather than working on underlying movements or skills. For long term goals, this may mean setting smaller, achievable goals that work towards the long term goal.

Practicing goals within real life contexts, such as at home or school, and practicing with the equipment or objects that the child uses everyday leads to greater success

Practice outside of therapy is hard work for families, but in order for goals to be achieved, practice needs to occur more regularly than just during therapy sessions.

Talk to your team about how much practice is likely to be needed. Together, come up with a plan for when and where this practice can realistically happen for your family. Consider supports that may be able to help with this plan, such as friends, siblings, school or extended family members.

WORKING TOGETHER AS PART OF A TEAM

Clinicians should share their knowledge about evidence-based intervention options that are appropriate for you/your child based on their abilities and goals. This will enable you to make informed decisions about which intervention suits you best. Some interventions may not be appropriate for you/your child at that time, and clinicians can help you understand why that is.

Families should be given choices and flexibility around services.

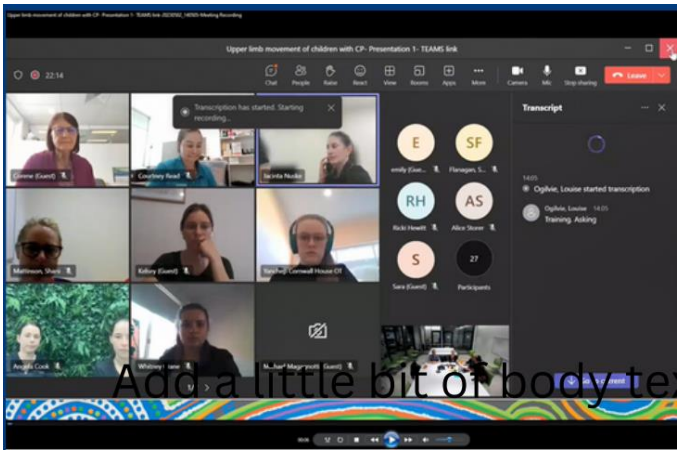
Clinicians working with you/your child should collaborate as a team, with your family included as an integral part of the team.

Clinicians communicating effectively around current priorities and intervention plans can ensure everyone is working towards common goals and reduce the burden on families around coordinating services.

Education Spotlight

Upper Limb Movement of Children with Cerebral Palsy – An Occupational Therapy Perspective

Louise Ogilvie and Simon Garbellini developed an education series to provide Occupational Therapists working in the field of CP with information regarding upper limb classifications and assessments to guide the right evidenced based intervention at the right time. Louise and Simon are Occupational Therapists, with more than 40 years of combined experience working within the Cerebral Palsy Mobility Service of Kids Rehab WA. The education was developed due to an identified lack of educational for community based Occupational Therapists regarding introductory information for managing arm and hand impairment for children with CP. Louise and Simon recently presented the education sessions online, as per the screen shot below, to 31 community and PCH Occupational Therapists. The series consisted of sessions covering: the definition and upper limb classification of CP; upper limb assessments; evidence based upper limb interventions (over two sessions); and a final interactive session.



Feedback from the participants included:

"I found today's session super helpful and engaging, thanks so much, looking forward to the next one."

"Thank-you for the fantastic PD! It was so informative and had that perfect balance of structured frameworks, videos, case studies and interaction. I was impressed with the interactive polls."

"Great PD, very informative and summarised the assessment and intervention for kids with CP well."

"A big thank you to you all for such a great UL PD and for all your hard work in getting this together. It was so helpful to know what assessments and approaches are used @ PCH and the NHDC classification systems has been so helpful".

Staff Spotlight

Dr Sarah Hall – Early Career Clinical Researcher

Sarah Hall is a Clinical Neuropsychologist and Post-Doctoral Research Fellow at Curtin University and Kids Rehab WA. She joined the Early Moves team in 2021, coordinating the expansion of the project to the new St John of God Hospital site in Midland. She has also overseen the establishment of the two-year-old developmental assessment clinic and enjoys the opportunity to conduct the occasional Bayley-4 assessment herself when required!

Sarah completed her PhD, which investigated social and emotional changes after acquired brain injury, at the University of Melbourne in 2018. She is particularly interested in research that has the potential to change policy and practice, delivering outcomes with real-world impacts for children and families. Prior to moving to Perth in 2021, she led several knowledge translation and quality improvement projects in Melbourne, including strengthening hospital responses to family violence, developing a new autism care planning process, and implementing evidence-based approaches to mood screening after stroke.

In addition to her research position, Sarah currently works part-time on the Neurosciences Unit Paediatric Diagnostic Team within the North Metropolitan Health Service. In this role, she conducts neuropsychological assessments and brief interventions with school-aged children who are having difficulties with their thinking, learning or behaviour associated with a known or suspected neurological disorder. She has seen first-hand how a lack of early assessment and support can lead to a cascade of challenges for at-risk children and their families. This underscores the importance of research like Early Moves – paving the way for early intervention so that children can have the best possible start to life.

Karen Twyford – PhD Candidate

Karen has always been interested in exploring how music therapy impacts the many different client groups that she has worked with over her career as a music therapist, both in the community and in hospital settings. Karen is also curious about understanding what music therapy brings to different team working models, and how it can be incorporated into multi-, inter- and transdisciplinary practices. Contributing to the evidence base for music therapy in paediatric acquired brain injury (ABI) is something that Karen feels is important, especially as little empirical evidence exists. Therefore, Karen has commenced a PhD. Initial discussions with her supervision team made Karen realise that it was possible to research the work that she does here at PCH, which was an exciting prospect.

Karen's PhD involves three studies which aims to understand the breadth and role of music therapy across the spectrum of rehabilitation in a tertiary hospital setting, specifically for children and adolescents with an ABI. A scoping review will be conducted initially to explore the current evidence base for music therapy in paediatric neurodisability and to identify research opportunities for specific areas of function. Realist evaluation will then examine the 'what, why and how' music therapy impacts patient outcomes and contributes to interprofessional treatment teams. Lastly, single case experimental design will examine if children and adolescents with an ABI who access music therapy during an outpatient admission in a tertiary hospital setting experience improved functional gains in an identified area. This study will seek to determine if a causal relationship between music therapy treatment and patient outcomes exists. Knowledge translation will be an important part of the research and findings will be shared with families, PCH staff, music therapists and the wider health community as appropriate.

While at times this feels like an immense undertaking, overall Karen is enjoying the work so far, and is very grateful for the wonderful ongoing support of her supervision team, which includes Dr Ashleigh Thornton, Professor Jane Valentine, Dr Suzi Taylor and Dr Jonathan Pool (Anglia Ruskin University, UK).

Dr Simon Garbellini – Research Coordinator

Simon has been working as an occupational therapist for 30 years, with more than 15 years in the Cerebral Palsy Mobility Service in Kids Rehab WA. Simon completed his PhD in 2020 through Australian Catholic University with his work embedded in a national multi-centre randomised controlled trial investigating the use of hand orthoses for children with cerebral palsy. Simon continues to work as a senior occupational therapist but has taken on a part-time research coordinator role within Kids Rehab WA. In the research coordinator role, Simon is working to develop research partnerships between Curtin University's School of Allied Health and Kids Rehab WA aimed at clinically embedding neurodevelopmental disability research within Kids Rehab WA programs. The research coordination role includes partnering with Kids Rehab WA and Curtin staff to plan, facilitate and coordinate research and quality improvement activities.

In collaboration with Curtin staff, Simon is supervising two occupational therapy Honours projects. This connection between Kids Rehab and Curtin provides a distinctive student experience for learning in a health environment, fosters relationships and builds capacity of staff for future honours project and post graduate supervision collaborations. A particular focus for Simon has been striving to develop sustainable and integrated quality improvement projects through the revitalisation of a quality improvement committee in Kids Rehab WA.

Knowledge Translation

Research Implementation

The Accelerate Project, funded by Perth Children's Hospital Foundation

The aim of the Accelerate Project was to evaluate implementation of the PCH "at risk of CP" service within the state-wide Kids Rehab WA, Early Intervention Service. We tracked a longitudinal cohort to measure fidelity of the service in implementation of the early intervention clinical practice guidelines and worked with consumers to identify mediators and barriers to successful implementation. Specific project outcomes were;

Objective One: To enable data collection and audit whether the core components of the early intervention "at risk" of CP services are being delivered as intended

To complete this objective, additional fields were added to the Paediatric Rehabilitation Information System (PRIS) to enable data collection and analysis of the guideline assessments and interventions. Data entry processes were reviewed and updated, and a data dictionary developed. Analysis of the extended audit data collected until 31/12/2019 was completed. Mapping of the data collection pathways has increased clinical knowledge and engagement with the data processes, and led into a prospective review of the early intervention service clinical pathways.

Objective Two: The Canadian Occupational Performance Measure (COPM) has been selected as one tool to determine the developmental trajectories and functional outcomes from birth to 24 months of the children who were identified "at-risk of CP".

Training in use of the Canadian Occupational Performance Measure (COPM) was completed and the tool is being implemented by early intervention clinicians. A Goal Setting working group was established and will continue its work to implement, monitor and evaluate use of the tool in the clinical service.

Parent and carer COPM satisfaction data collection was completed in July 2021 and analysed in September 2021 and showed very high consumer satisfaction with the early intervention service.

The opportunity to evaluate implementation of the clinical guidelines for early detection of CP has provided information to guide clinical practice, informed by the voice of consumers, which aims to improve the outcomes of children at risk of CP and their families. Key knowledge translation activities to ensure the outcomes are sustained beyond the completion of the project include:

1. Early intervention clinicians have been trained in contemporary best practice early detection and intervention during the implementation process, increasing their competency. As research has been embedded into the clinical service this has increased clinicians' exposure and skills in research and knowledge translation.

2. A Community of Practice for the General Movements Assessment (GMA) has been established to share knowledge and act as a consultation service for clinicians around the state.

3. As a result of successful implementation of the clinical guidelines at PCH, our next aim is to develop a state-wide teaching and training network so that all Western Australian children at risk of CP have equitable access to evidence based early detection and early intervention in the right place at the right time.

As a team, we have learned that the use of a clinical working group to guide early design and project decisions was crucial to implementation and development of stakeholder networks. Further, consumer input to design the service using Focus Groups, ongoing guidance from the Kids Rehab WA Consumer Group and feedback on service evaluation from the parent satisfaction survey all provided important information used in this project.

We thank the Perth Children's Hospital Foundation for their support for this work, through a Research Implementation Grant (ID9805), and for their future support for its next stages, through an Education and Training Grant (ID10088)

Research Implementation

ENVISAGE (Enabling Visions and Growing Expectations) A national rollout funded by the Department of Social Services

The ENVISAGE Consortium, led by Australian Catholic University (ACU) (Associate Professor Laura Miller and Professor Christine Imms), were successful in securing $6.9 million in funding from the Department of Social Services to deliver ENVISAGE across all states and territories in Australia for the next two years. The media release from ACU can be found here: $13.8 million to support children with disability or emerging developmental concerns | Department of Social Services Ministers (dss.gov.au). The consortium includes research, health and community services. CAHS are the Consortium member for WA (lead member Professor Jane Valentine), working with Kiind and Kids Are Kids as sub-contractors on this project to deliver the program to families in WA.

ENVISAGE provides caregivers raising a child 0-8 years old with a disability or developmental concerns with early exposure to current thinking and best practices about childhood disability and encourages information-sharing and connections among families and service providers. Each workshop is informative, while empowering caregivers to recognise their own capacities, goals, competence, and capabilities to parent their child with an early-onset Neurodevelopmental Disability (NDD). The workshops address broad themes, but do not offer clinical services or advice to families about personal or child-specific matters.

The themes include:

- modern concepts and thinking about health: World Health Organisation's International Classification of Functioning (ICF) and its 'F-words' adaptation
- the centrality of 'family' in paediatric practice
- the importance of 'development' of child, siblings and family
- transactional relationship-informed approaches among child, family and environment
- the challenges and complexities of parenting a child with an impairment
- the importance of caregiver self-care, ways of thinking about it, and tools, and
- communicating, collaborating, and connecting effectively with others.

For more information, visit https://envisage.community/

Current Competitive Grants

Grant	Funding	Ends	Study
Grants led by Kids Rehab WA			
PCH Foundation	$156,810.98	2023	Developing a sustainable family- clinician- researcher network for education and training in the early detection of cerebral palsy for all infants in Western Australia. (**Jane Valentine, Alison Salt, Sue-Anne Davidson, Ashleigh Thornton**, Andrew Savery, Mary Sharp, Antony Clark, **Tiffany Grisbrook, Catherine Elliott**)
MRFF – Primary Health Care Research	$1.58m	2027	CP Movetime. (**Catherine Elliott, Dayna Pool**, Stewart Trost, Christine Imms, Olaf Verscuren, Sarah Reedman, Ben Jackson, Amity Campbell, Mark Peterson, Ewan Cameron, Rachael Moorin, Siohan Reid, **Jane Valentine**, **Ashleigh Thornton**, Leon Straker)
Enabling Allied Health Research Capacity - Chief Allied Health Office and WA Health Translation Network	$30k	2026	Functional outcome following orthopaedic surgery for gait correction in children with cerebral palsy at an activity and participation level. **(Maxine Fong)**
PCH Foundation	$10k	2022	Visible: Vision Intervention for Seeing Impaired Babies: Learning Through Enrichment. (**Alison Salt, Lynne Jensen, Catherine Elliott, Jane Valentine, Sue-Anne Davidson, Ashleigh Thornton.** This grant is linked to a international study led by Professor Roslyn Boyd, Assoicate Professor Andrea Guzzetta, Professor Iona Novak, Dr Cathy Morgan, Professor Glen Gole and Dr Susan Greaves.)
NHMRC Clinical Trials and Cohort Studies	$2.2m	2024	Early Moves: A prospective cohort study to identify an early biomarker for cognitive impairment. (**Catherine Elliott**, **Jane Valentine**, Alicia Spittle, Roslyn Boyd, Nadia Badawi, Catherine Morgan, Desiree Silva, Elizabeth Geelhoed, Robert Ware, Svetha Venkatesh.)
PCH Foundation	$1.5m	2025	Early Moves. **(Catherine Elliott, Jane Valentine)**
PCH Foundation; Research Project Grant	$78k	2022	GAME: Goals, Activity, Motor Enrichment early intervention for infants with cerebral palsy. **(Catherine Elliott, Roslyn Ward, Jane Valentine, Misty Blakeman)**
PCH Foundation	$143k	2022	Accelerate: Early Diagnosis of Babies at Risk of CP. (**Roslyn Ward; Jane Valentine; Catherine Elliott; Sue-Anne Davidson; Alison Salt; Ashleigh Thornton; Wendy Langford;** Mary Sharp; Elizabeth Geelhoed; Courtenay Harris)

Grants led by other institutions			
MRFF – Chronic Musculoskeletal Conditions in Children and Adolescents	$2.498m	2027	Australian Cerebral Palsy Musculoskeletal Health Network. (Prof Craig Munns, Prof Roslyn Boyd, Prof Stewart Trost, Assoc Prof Kylie Tucker, Assoc Prof Leanne Sakzewski, Assoc Pro Tracy Comans, Prof Peter Pivonka, Assoc Prof Judith Little, Prof Natasha Nassar, Prof Joshua Burns, Prof Nadia Badawi, Dr Simon Paget, Porf Robert Ware, Dr Kate Willoughby, **Dr Katherine Langdon** [Site Lead], Dr Heather Burnett)
Department of Health (Western Australia) -	$392K	2024	Detecting pain in kids who can't tell you it hurts: PainChek for children with disabilities. (Assoc Prof Jenny Downs, Dr Marie Blackmore, Dr Jeff Hughes, **Dr Katherine Langdon** [Site lead]**, Nadine Smith**, Janet Jonas-Oliver, Assoc Prof David Sommerfield, Prof Fiona Wood, Prof Britta Regli-von Ungern-Sternberf, Peter Jacoby)
National Health and Medical Research Council	$1.537m	2026	Reducing potentially preventable hospitalisations and building health literacy for children and adolescents with intellectual disability. (Assoc Prof Jenny Downs, **Dr Katherine Langdon** [Site lead])
MRFF Maternal First 2,000 Days and Childhood Health	$1.44m	2025	SCHOOL READINESS: 4-5 year old follow-up of randomised trials of Neuroprotection and Neurorehabilitation for children at risk of cerebral palsy. (Prof Roslyn Boyd, Prof Iona Novak, Dr Catherine Morgan, Assoc Prof Leanne Sakzewski, Assoc Prof Michael Fahey, Prof Robert Ware, Assoc Prof Tracy Comans, Dr Koa Whittingham, Prof Stewart Trost, Dr Kerstin Pannek). Site Leads: **Tiffany Grisbrook** and **Alison Salt**
National Health and Medical Research Council	$3.1m	2026	Cognitive Improvement through early Restoration of cirCADian rhythms in very preterm Infants via Environmental Modification: The CIRCA DIEM Study. Led by the University of Western Australia. (Professor Jane Pillow, Professor Rod Hunt, Professor Peter Anderson, Dr Peter Mark, Professor Alicia Spittle, Professor Andrew Whitehouse, Dr Julie Marsh, **Professor Catherine Elliott**, Professor Nadia Badawi)
National Health and Medical Research Council	$2.4m	2026	ACTIVE STRIDES-CP: Randomised trial of Intensive Rehabilitation (Combined Intensive Gait and Cycling Training) for children with moderate to severe bilateral cerebral palsy. Led by the University of Queensland. (Sakzewski, Boyd, **Elliott**, Novak, **Pool**, Trost, Ware, Comans, Toovey, Peterson)
WA Child Research Fund	$250k	2022	Cognitive Improvement through early Restoration of cirCADian rhythms in very preterm Infants via Environmental Modification: The CIRCA DIEM Study. (Professor Jane Pillow, Professor Rod Hunt, Professor Peter Anderson, Dr Peter Mar, Professor Alicia Spittle,

			Professor Andrew Whitehouse, Dr Julie Marsh, **Professor Catherine Elliott**, Professor Nadia Badawi)
Perron Foundation	$1m	2025	WA National Imaging Facility Node. (Prof Timothy Colmer, Prof Gary Geelhoed, Prof Francis Roslyn, Prof Paul Parizel, Dr Nick Gottardo, Dr Michael Bynevelt, **Dr Jane Valentine**, **Prof Catherine Elliott)**
PCH Foundation	$2.8m	2026	Move to Improve: Multidirectorate CAHS program on exercise in chronic illness. (Prof Elizabeth Davis (Child and Adolescent Health Service), Prof Fiona Wood, **Prof Jane Valentine**, Dr Thomas Walwyn, Ms Kim Laird (Child and Adolescent Health Service), **Prof Catherine Elliott (Curtin University)**, Ms Joanna White (Child and Adolescent Mental Health Service), Dr Treya Long (Fiona Wood Foundation), Dr Louise Naylor (University of Western Australia), Dr Amy Finlay-Jones (Telethon Kids Institute)
NHMRC Project Grant	$601k	2022	HABIT-ILE: A randomised trial of Hand Arm Bimanual Intensive Training Including Lower Extremity training for children with bilateral cerebral palsy. (Leanne Sakzewski, **Catherine Elliott**, Roslyn Boyd, Jenny Ziviani, Iona Novak, Stewart Trost)
NHMRC Project Grant	$827k	2022	Participate CP: Optimising participation in physically active leisure for children with cerebral palsy: A randomised controlled trial. (Leanne Sakzewski, **Catherine Elliott**, Roslyn Boyd, Jenny Ziviani, Iona Novak, Stewart Trost, Annette Majnemer)
Canadian Institutes of Health Research	$646K	2024	ENAbling VISions And Growing Expectations for Service Providers (ENVISAGE-SP): Creating opportunities to change how service providers think, talk about, and approach childhood disability in the 21st century. (Peter Rosenbaum, Kim Herketh, Rachel Martens, Laura Miller) [Site Lead: **Jane Valentine**]

Publications

July 2021 – June 2022

(in alphabetical, first author order)

Dale, N., **Salt, A.**, Sargent, J., & Greenaway, R. (Eds.). (2022). Children with vision impairment: assessment, development and management (1 ed.). John Wiley and Sons.

Fortnum, K., Reid, S., **Elliott, C.**, Furzer, B., Wong, J., & Jackson, B. (2022). Physical activity participation among children diagnosed with mental health disorders: A qualitative analysis of children's and their guardian's perspectives. Qualitative Research in Sport, Exercise and Health, 14(5), 724-743. https://doi.org/10.1080/2159676X.2021.1961848

Harvey, A. R., McKinnon, C. T., **Smith, N.**, Ostojic, K., Paget, S. P., Smith, S., Shepherd, D. A., Lewis, J., & Morrow, A. (2022). Establishing consensus for the assessment of chronic pain in children and young people with cerebral palsy: a Delphi study. Disability and Rehabilitation, 44(23), 7161-7166. https://doi.org/10.1080/09638288.2021.1985632

Honan, I., Finch-Edmondson, M., Imms, C., Novak, I., Hogan, A., Clough, S., Bonyhady, B., McIntyre, S., **Elliott, C.**, Wong, S., Bink, M., & Badawi, N. (2022). Is the search for cerebral palsy 'cures' a reasonable and appropriate goal in the 2020s? [Review]. Developmental Medicine and Child Neurology, 64(1), 49-55. https://doi.org/10.1111/dmcn.15016

Imms, C., Wallen, M., **Elliott, C.**, Hoare, B., Greaves, S., Randall, M., & Orsini, F. (2022). Implications of providing wrist-hand orthoses for children with cerebral palsy: evidence from a randomised controlled trial [Article]. Disability and Rehabilitation. https://doi.org/10.1080/09638288.2022.2079734

Jackman, M., Sakzewski, L., Morgan, C., Boyd, R. N., Brennan, S. E., **Langdon, K.**, Toovey, R. A. M., Greaves, S., Thorley, M., & Novak, I. (2022). Best evidence for improving function in children with cerebral palsy: Success is within reach. Dev Med Child Neurol, 64(5), 664-665. https://doi.org/10.1111/dmcn.15186

Jackman, M., Sakzewski, L., Morgan, C., Boyd, R. N., Brennan, S. E., **Langdon, K.**, Toovey, R. A. M., Greaves, S., Thorley, M., & Novak, I. (2022). Interventions to improve physical function for children and young people with cerebral palsy: international clinical practice guideline. Developmental Medicine & Child Neurology, 64(5), 536-549. https://doi.org/https://doi.org/10.1111/dmcn.15055

Khaksar, S., Pan, H., Borazjani, B., Murray, I., Agrawal, H., Liu, W., **Elliott, C.**, Imms, C., Campbell, A., & Walmsley, C. (2021). Application of inertial measurement units and machine learning classification in cerebral palsy: Randomized controlled trial [Article]. JMIR Rehabilitation and Assistive Technologies, 8(4), Article e29769. https://doi.org/10.2196/29769

Marpole, R., **Langdon, K.**, & Wilson, A. (2022). Gastrostomy feeding in children with severe cerebral palsy in Western Australia. Acta Paediatrica, 111(3), 680-681. https://doi.org/https://doi.org/10.1111/apa.16214

McCall, J. V., Ludovice, M. C., **Elliott, C.**, & Kamper, D. G. (2022). Hand function development of children with hemiplegic cerebral palsy: A scoping review [Review]. Journal of Pediatric Rehabilitation

Medicine, 15(1), 211-228. https://doi.org/10.3233/PRM-200714

McLean, B., Taylor, S., **Valentine, J**., Carey, L., **Thornton, A**., & **Elliott, C**. (2021). Somatosensory discrimination impairment in children with hemiplegic cerebral palsy as measured by the sense_assess© kids. Australian Occupational Therapy Journal, 68(4), 317-326. https://doi.org/https://doi.org/10.1111/1440-1630.12729

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Reedman, S. E., Jayan, L., Boyd, R. N., Ziviani, J., **Elliott, C**., & Sakzewski, L. (2022). Descriptive contents analysis of ParticiPAte CP: a participation-focused intervention to promote physical activity participation in children with cerebral palsy. Disability and Rehabilitation, 44(23), 7167-7177. https://doi.org/10.1080/09638288.2021.1985636

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Taylor, S., **Elliott, C**., **McLean, B**., Parsons, R., Falkmer, T., Carey, L. M., Blair, E., & Girdler, S. (2022). Construct validity, reliability, and responsiveness of the Wrist Position Sense Test for use in children with hemiplegic cerebral palsy [Article]. Australian Occupational Therapy Journal. https://doi.org/10.1111/1440-1630.12825

Thornton, A. L., Hackett, E., Wilkie, A., Gallon, J., **Grisbrook, T. L**., **Elliott, C**. M., & Ciccarelli, M. (2022). A qualitative exploration of motivations and barriers for community leisure organisations' engagement with the Jooay™ mobile app [Article]. Disability and Rehabilitation, 44(9), 1737-1745. https://doi.org/10.1080/09638288.2021.1986581

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July 2022 – June 2023

(in alphabetical, first author order)

Boyd RN, Ziviani J, Sakzewski L, Novak I, Badawi N, Pannek K, **Elliott C**, Greaves S, Guzzetta A, Whittingham K, **Valentine J**, Morgan C, Wallen M, Eliasson AC, Findlay L, Ware R, Fiori S, Rose S. REACH: study protocol of a randomised trial of rehabilitation very early in congenital hemiplegia. BMJ Open. 2017;7(9):e017204.

Carozza L, Anderson-Mackay E, Blackmore AM, Kirkman HA, Ou J, **Smith N**, Love S. Chronic Pain in Young People With Cerebral Palsy: Activity Limitations and Coping Strategies. Pediatr Phys Ther. 2022;34(4):489-95.

Crebbin K, **Grisbrook T, Elliott C, Thornton A.** The Use of Serious Gaming to Improve Sensorimotor Function and Motivation in People with Cerebral Palsy: A Systematic Review. Games Health J. 2023;12(3):169-97.

Davidson SA, Ward R**, Elliott C, Harris C,** Bear N, **Thornton A, Salt A, Valentine J, EI Group**. From guidelines to practice: A retrospective clinical cohort study investigating implementation of the early detection guidelines for cerebral palsy in a state-wide early intervention service. BMJ Open. 2022;12(11):e063296.

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Martin T, McIntyre S, Waight E, Baynam G, Watson L, **Langdon K**, Woolfenden S, Smithers-Sheedy H, Sherwood J, Group AB-EV. Prevalence and trends for Aboriginal and Torres Strait Islander children living with cerebral palsy: A birds-eye view. Dev Med Child Neurol. 2023.

Morgan C, Badawi N, Boyd RN, Spittle AJ, Dale RC, Kirby A, Hunt RW, Whittingham K, Pannek K, Morton RL, Tarnow-Mordi W, Fahey MC, Walker K, Prelog K, **Elliott C, Valentine J,** Guzzetta A, Olivey S, team Gs, Novak I. Harnessing neuroplasticity to improve motor performance in infants with cerebral palsy: a study protocol for the GAME randomised controlled trial. BMJ Open. 2023;13(3):e070649.

Sakzewski L, **Pool D**, Armstrong E, Reedman SE, Boyd RN, **Elliott C**, Novak I, Trost S, Ware RS, Comans T, Toovey R, Peterson MD, Kentish M, Horan S, **Valentine J**, Williams S. ACTIVE STRIDES-CP: protocol for a randomised trial of intensive rehabilitation (combined intensive gait and cycling training) for children with moderate-to-severe bilateral cerebral palsy. BMJ Open. 2023;13(3):e068774.

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Steel DBD, Danti FR, Abunada M, Kamien B, Malhotra S, Topf M, Kaliakatsos M, **Valentine J**, Nemeth AH, Jayawant S, Reid KM, Mankad K, Sudhakar S, Ben-Pazi H, Barwick K, Kurian MA. Clinical Phenotype

in Individuals With Birk-Landau-Perez Syndrome Associated With Biallelic SLC30A9 Pathogenic Variants. Neurology. 2023;100(21):e2214-e23.

Tofts LJ, Armstrong JA, Broley S, Carroll T, Ireland PJ, Koo M, **Langdon K**, McGregor L, McKenzie F, Mehta D, Savarirayan R, Tate T, Wesley A, Zankl A, Jenner M, Eyles M, Pacey V. Australian guidelines for the management of children with achondroplasia. J Paediatr Child Health. 2023;59(2):229-41.

Ward R, Barty E, Hennessey N, **Elliott C**, **Valentine J**. Implementation of an Early Communication Intervention for Young Children with Cerebral Palsy Using Single-Subject Research Design. J Clin Med. 2022;12(1).

Conference Presentations

REACH: randomised comparison trial of rehabilitation early for congenital hemiplegia. **Australasian Academy of Cerebral Palsy and Developmental Medicine and the International Alliance of Academies of Childhood Disability, Melbourne, VIC Australia, 1-5 March 2022**.

Boyd, R., Sakzewski, L., Greaves, S., Novak, I., Wallen, M., Ziviani, J., Findlay, L., Morgan, C., Elliott, C., Eliasson, A. C., Badawi, N., Heathcock, J., Maitre, N., and Gillick, B. (2022).

Paediatric Stroke: A single-centre summary of clinical profile, medical and allied health management, and sub-acute rehabilitation outcomes

Stroke Society of Australasia, Perth, October 2021
Sam Armstrong*, Jane Valentine, Renae Dayman, Simon Williams, Sharon Lee, Sue-Anne Davidson, Rae Robinson

Implementation of early detection and early intervention for babies at risk of cerebral palsy at Perth Children's Hospital in Western Australia: a service evaluation

CAHS Child Health Research Symposium, Perth, November 2021
Sue-Anne Davidson*, Roz Ward, Catherine Elliott, Courtenay Harris, Natasha Bear, Alison Salt, Kids Rehab WA Early Intervention team, Ashleigh Thornton and Jane Valentine.

IQ and Adaptive Functioning profiles of Western Australian Children with Cerebral Palsy within a Rehabilitation Mobility Clinic

CAHS Child Health Research Symposium, Perth, November 2021
Kassandra Hewitt*, Jonson Moyle, Katherine Langdon, Ashleigh Thornton, Belinda McLean, Donna Bayliss

Targeted movement interventions can improve pain in children with dyskinetic cerebral palsy. A feasibility single subject research design

CAHS Child Health Research Symposium, Perth, November 2021
Nadine Smith*, Simon Garbellini, Natasha Bear, Ashleigh Thornton, Peta Watts, Noula Gibson

Identification of functional outcome measures in gait corrective surgery for children with CP.

Australisian Academy of Cerebral Palsy and Developmental Medicine, Melbourne, March 2022
Maxine Fong*, Sian Williams, Lynn Jensen, Noula Gibson

Targeted movement interventions can improve pain in children with dyskinetic cerebral palsy. A feasibility single subject research design

Australisian Academy of Cerebral Palsy and Developmental Medicine, Melbourne, March 2022
Nadine Smith*, Simon Garbellini, Natasha Bear, Ashleigh Thornton, Peta Watts, Noula Gibson

Implementation of early detection and early intervention for babies at risk of cerebral palsy at Perth Children's Hospital in Western Australia: a service evaluation

Rehabilitation Medicine Society of Australia and New Zealand, Gold Coast, June 2022
Sue-Anne Davidson*, Roz Ward, Catherine Elliott, Courtenay Harris, Natasha Bear, Alison Salt, Kids Rehab WA Early Intervention team, Ashleigh Thornton and Jane Valentine.

*Kids Rehab WA presenter

Awards and Degrees

Currently Enrolled

Student	Affiliation	Degree	Collaborating Institution(s)	Project
Sue-Anne Davidson	Curtin	PhD	PCH	Development of a state-wide clinical education and training network to improve very early detection and intervention for babies at risk of cerebral palsy in Western Australia; Accelerate WA
Emma Mill	Curtin	PhD	PCH (Kids Rehab and Burns Service WA), TKI	Assessing somatosensory function in children following hand burns
Maxine Fong	Curtin	MPhil	PCH	Establish functional outcome measures for children with CP undergoing surgery for gait correction in clinical practice
Evelyn Toh	Curtin	MPhil	PCH	Parent quality of life and developmental outcomes of young children
Yvette Pickering	Curtin	MPhil	PCH	Recreational prosthetic use in children and adolescents with upper limb difference[2]
Emily	Curtin	MPhil	TBC	
Christina	Curtin	MPhil	TBC	
Nadine Smith	UWA	PhD	PCH	Pain measurement for all young people with cerebral palsy: What is needed for a best practice bio-psychosocial model to capture impact of pain on function and participation?[1]
Karen Twyford	UWA	PhD	PCH	The impact of music therapy across the rehabilitation spectrum in paediatric acquired brain injury: A mixed methods experimental enquiry
Natasha Bear	UWA	PhD	TKI, PCH	Respiratory hospitalisations in children and young people with cerebral palsy: Which children and at what cost?

Kassandra Hewitt	UWA	PhD	PCH	Examining the links between somatosensation and cognition in children with cerebral palsy (CogSense study)

[1] Funded by NHMRC Centre for Research Excellence: Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with cerebral palsy ("CP-Achieve")
[2] Funded by Perth Children's Hospital Foundation

Key Links

Kids Rehab WA Website

Kids Rehab WA Website

Project Links

Early Moves

Optimising Participation in Physically Active Leisure for Children with Cerebral Palsy: A Randomised Controlled (ParticiPAte CP)

Visible: Vision Intervention for Seeing Impaired Babies: Learning Through Enrichment

Other Key Links

Australasian Cerebral Palsy Clinical Trials Network

Curtin enAble Institute

Telethon Kids Institute – Chronic Disease Research Focus Area

This document can be made available in alternative formats on request for a person with a disability.

Child and Adolescent Health Service
Telephone: (08) 6456 5605
Produced by Kids Rehab WA; Ashleigh Thornton, Tiffany Grisbrook, Simon Garbellini