

# CP-ACHIEVE FINAL REPORT



# 2025

# Executive Summary

## A message from Dinah Reddihough

As the CP-Achieve program officially comes to an end, we want to take a moment to reflect on the journey we've shared and the remarkable impact we've made together. When CP-Achieve first began, we had a bold vision: to better understand and improve the lives of young people with cerebral palsy aged 10 to 30 years. Today, we look back with pride at how far we've come.



Over the past few years, our team has accomplished significant outcomes. We've completed a wide range of projects, shared our findings through published papers and presentations, and secured vital research funding. Behind these achievements is a group of dedicated researchers and consumer partners who have worked hard to develop evidence to improve the lives of young people with cerebral palsy.

We've listened to the voices of young people and their families and used those insights to shine a light on a whole range of issues important to young people with cerebral palsy. From health and wellbeing to community participation and access to services, our work is helping shape a clearer, more accurate picture of what these young people require. With targeted research, we've been able to explore their unique experiences and bring their needs to the forefront of national and international conversations.

Just as important has been the way we've worked. Consumer engagement was at the heart of everything we did. We've built a community of consumer partners and together, we've co-created an outstanding resource, and built a collaborative, passionate network of people committed to making lasting change. Along the way, we've also nurtured new talent. A group of fresh, enthusiastic researchers has joined the field, ready to continue pushing boundaries and asking the important questions.

While this chapter is closing it is not the end and so much more needs to be done. Moving forward, we need to be powerful advocates for people with cerebral palsy. We need to address every opportunity both to secure funding and to work in partnership with consumers to improve the health, wellbeing and participation of everyone with cerebral palsy and their families.

Thank you,

*Dinah S. Reddihough*

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# What was CP-Achieve

CP-Achieve was a five-year research program dedicated to improving the health, wellbeing, and life outcomes of adolescents and young adults with cerebral palsy, aged 10-30 years

CP-Achieve was funded by the National Health and Medical Research Council, from February 2020 to June 2025.

It supported collaborative research and capacity building in cerebral palsy, bringing together young people with cerebral palsy, their families, clinicians, researchers, and students to work toward shared goals.

The program focused on understanding the physical and mental health challenges faced by young people with cerebral palsy, as well as identifying the outcomes that matter most to them.

This knowledge informed the development of practical programs for health and disability service providers, improved access to health and community services, and guided policy and practice to better support young people with cerebral palsy.



*Photograph submitted by Nofar Ben Itzhak for the AusACPDM and CP-Achieve 2024 Lived Experience Photo Exhibition*

# Our Team

The team consisted of a multidisciplinary group of clinicians, researchers and consumers who have worked together to achieve CP-Achieve's aims

## Chief Investigators

Dinah Reddihough, Christine Imms, David Coghill, Ingrid Honan, Kerr Graham, Margaret Wallen, Nora Shields, Prue Morgan, Rob Carter, Susan Sawyer

## Associate Investigators

Bruce Bonyhady, Evelyn Culnane, Gabrielle Drake, Jan Willem Gorter, Jane Tracy, Leanne Johnston, Leanne Sakzewski, Lyndal Hickey, Mats Granlund, Peter Rosenbaum, Jenny Ziviani

## Postdoctoral Research Fellows

Stacey Cleary, Carlee Holmes, Iain Dutia, Robbie Eres, Sarah Giles, Gaela Kilgour, Melissa Mulraney

## Knowledge Translation Fellows

Georgia McKenzie, Claire Rowland

## Consumer Involvement Coordinators

Sevastine Katsakis, Carolyn Pinto, Joan Gains

## Research Coordinators

Debora Markelis, Kari Klein

## CP-Achieve Postdoctoral Candidates

Jacinta Pennacchia, Jacqueline Ding, Megan Walsh, Nadine Smith, Georgia McKenzie

## Research Associates

Abby Thevarajah\*, Adam Scheinberg, Adrienne Harvey, Barry Rawicki, Dana Anaby, Darryl Sellwood, Elise Woodman, Gina Hinwood, Helen Bourke-Taylor, Ian Wong, James Czencz\*, Jessica Kramer, Jocelyn Cohen, John Carey\*, Kate Anderson, Kathleen Ooi, Loren Apokourastos\*, Loretta Sheppard, Michelle McInerney, Petra Karlsson, Rachel Toovey, Sue Reid, Utsana Tonmukayakul\*, Ximena Camacho

*\*Also an Associated Higher Degree Research Student*

## Associated Higher Degree Research Students

Katie Headrick, Rowan Johnson, Kerry Britt, Magnus Ivarsson

## **Steering Committee**

Dnah Reddihough, Chair; Christine Imms, Participation Theme Leader; Nora Shields, Workforce Theme Leader; Margaret Wallen, Consumer Involvement Theme Leader; Rob Carter, Economics Theme Leader; David Coghill, Program 1 Leader; Prue Morgan, Program 2 Leader; Joan Gains (to June 2022) / Carolyn Pinto (from August 2022), Consumer Coordinator; Kari Klein (to February 2022) / Debora Markelis (from March 2022), Executive Support

## **Stakeholder Advisory Group**

Nadia Badawi, Melissa Boekhoorn, Kerry Evans, Kate MacRae, Andrew Pope, Maria Velegrinis, Christine Imms, Dinah Reddihough, Amy Southwood, Scott Shepherd, Rob White, Anne-Marie Dickinson, Adrienne Fosang

## **One Group Our Voice Advisory Group**

Brodie Shaw, Penny Manning, Shiris Wong, Brenton Ponza

## **CP-Voice Advisory Group**

Feona Magtanum, Jet Johnson, Kyra Culloten, Kai Armstrong, Ivy Rogers, Sam Higgins, Lachlan Dosser

## **CP-Unite Advisory Group**

Nicole Kozelj, Alana Jovanovski, Greg Bonyhady, Rohan Symonds, Gaurav Thakkar, Cassandra Assaad, Alesia Lu, Freya Muzel, Shanee Holmwood, Abbey Potter, Natasha Jones, Tessa Pearce, Alice Verall, Lanie Dickson

## **Parent Advisory Group**

Janine Stanley, Kylie Brown, Michelle Roger, Bianca Brant, Wendy Pritchard, Ebonie Gough, Helen Briffa, Toni Green, Michelle King, Chris Pacheco, Joan Gains, Helen Tossell, Julie Dean, Meg Smith

## **Consumer Partners**

Alesia Lu, Alex Birnie, Alexa Yao, Amy Hogan, Ann Vouden, Bethany Green, Caitlyn Doyle, Cassandra Assaad, Chris Pacheco, Debbie Dorfan, Finn O'Keefe, Fiona Magtanum, Freya Munzel, Gaurav Thakker, Georgia Rose, Greg Bonyhady, Jet Johnson, Kylie Brown, Nicole Kozelj, Oliver Hunter, Rohan Symonds, Shirley Wong, Wendy Parker

# Our Partners

CP-Achieve was carried out in partnership with the following organisations



WESTERN SYDNEY  
UNIVERSITY



# CP-Achieve Snapshot

## CP-Achieve delivered collaboration, research, capacity building, and impact

CP-Achieve brought together a wide network of collaborators, investigators and consumers across Australia, delivering a range of outputs while focusing on building capacity to strengthen knowledge and skills within the sector. Supported by multiple grants, the research encompassed many projects, with ongoing initiatives continuing to advance this work.

### Collaborators



**59**

Investigators



**50**

Consumers



**14**

Organisations



**12**

Partnerships

### Outputs



**113**

Publications



**236**

Presentations



**43**

Webinars



**3**

Symposia

### Capacity building



**5**

PhD scholarships



**2**

Knowledge Translation Fellowships



**6**

Postdoctoral Fellows



**23**

Travel scholarships awarded

### Research



**13**

Grants



**41**

Projects

# Impact Highlights

CP-Achieve research directly shaped policy, practice, education, and community inclusion for people with cerebral palsy



## Uptake and use of evidence by decision-makers and transition services

Evidence was embedded into cerebral palsy specific *HealthPathways* and care planning tools, strengthening statewide clinical coordination and person-centred service delivery.

**Evelyn Culnane.** Transition and services for adults including care pathways



## Expanded access to inclusive physical activity opportunities

A pilot health literacy resource was adopted in the development of, *Fitness for Life*, an accessible website that builds skills and knowledge, and expands physical activity opportunities beyond rehabilitation settings.

**Jackie Ding- PhD Candidate.** Evidence-based lifestyle program.  
**Dr Stacey Cleary and Dr Georgia McKenzie.** *Fitness for Life*



## Primary care practice improvement

A systematic review informed the development of GP and consumer checklists to support structured consultations and consistent primary care service delivery for adults with cerebral palsy.

**Professor Prue Morgan.** Exploring the profile of general practice access and interventions among adults with cerebral palsy: A systematic review



## Uptake of Inclusive Consumer Involvement in Research Practice

Co-designed resources supported meaningful consumer involvement, including people who use augmentative and alternative communication, improving accessibility and authenticity, and strengthening inclusive research practice in health and disability research.

**Claire Rowland.** Navigating Consumer Involvement in Health and Disability Research

**Megan Walsh- PhD Candidate.** Inclusive Framework and Toolkit to include AAC users in research



## Exercise in complex disability uptake by policy and education

Research was translated into service delivery and workforce education, with outcomes informing community inclusion policy and initiatives (inclusive gym programs and accessible beach day). The evidence was also incorporated into university teaching on adults with cerebral palsy at University of New South Wales and Central Queensland University.

**James Czencz- PhD Candidate.** Exercise interventions for those with complex cerebral palsy



## Core Outcome Set for chronic pain in cerebral palsy impact on assessment

Development of standardised chronic pain assessment informed clinical guidelines, enabling equitable referral to multidisciplinary pain services for people with cerebral palsy.

**Nadine Smith- PhD Candidate.** Development of a Core Outcome Set to assess chronic pain for children and young people with cerebral palsy using a biopsychosocial approach

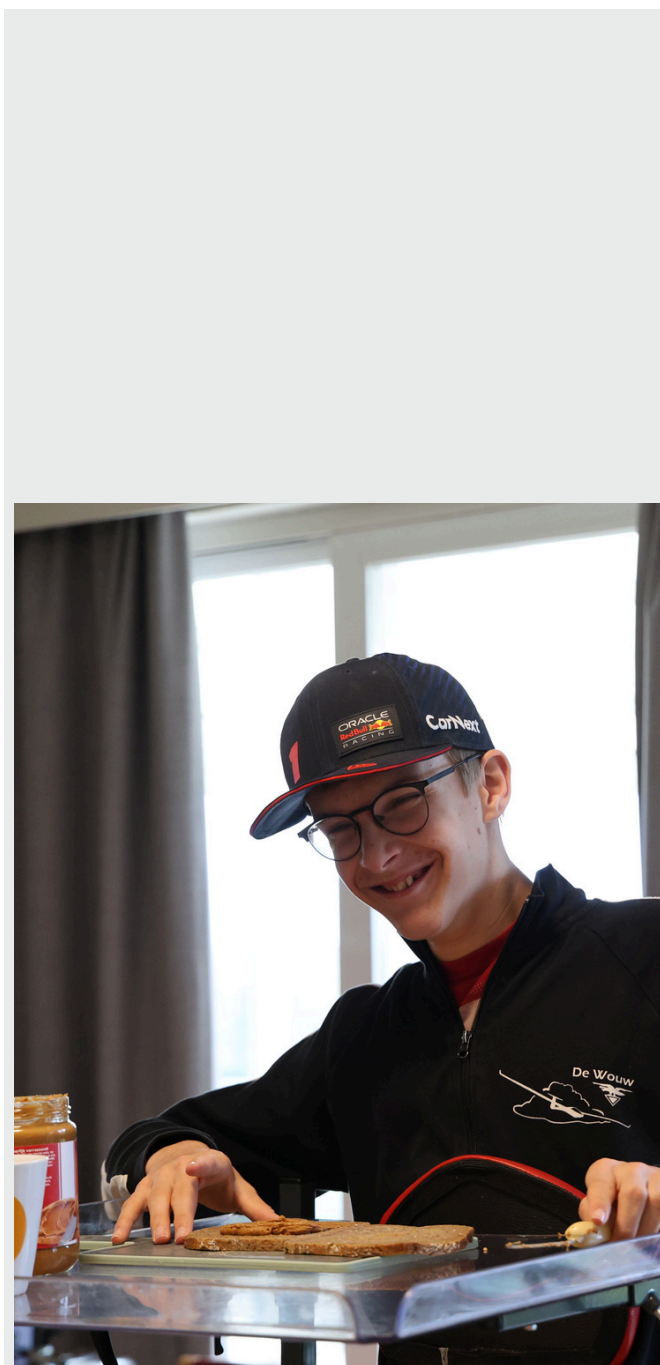
# CP-Achieve Themes

The impact of programs and projects was strengthened through the integration of four cross-cutting themes

To ensure the success and sustainability of our research outcomes across all CP-Achieve projects, we embedded cross-cutting themes that underpinned our approach.

The themes reflected our commitment to authentic consumer partnership, participation-focused design, economic accountability, and the development of a specialised health and medical research workforce equipped to continue advancing the field.

By integrating these elements throughout the program, we strengthened the relevance, rigour, and long-term impact of our work. Each theme played a critical role in ensuring that research efforts were meaningful, targeted, and ultimately translated into real-world improvements in the lives of young people with cerebral palsy and their families.



*Photograph submitted by Nofar Ben Itzhak for the AusACPDM and CP-Achieve 2024 Lived Experience Photo Exhibition*

# Theme: Promotion of Participation

## What we did

This theme focused on understanding and promoting participation as a key factor in supporting positive outcomes for young people with cerebral palsy. CP-Achieve aimed to encourage active participation by supporting fitness, recreation, meaningful social and community connections, and self-management of health needs.

To guide our work, we used the family of Participation Related Constructs (fPRC) framework, which helped us clearly define and measure participation. In the fPRC, participation is defined as having two essential elements:

attendance (being present in activities such as education, recreation, or employment) and involvement (the personal experience of participation, including engagement, persistence, and social connection). This distinction allowed us to better understand individual experiences and assess the impact of interventions.

Our research design, including the development of hypotheses, outcome measures, and discrete choice analysis, was shaped by this framework and aligned with the International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001, *International classification of functioning, disability and health*).

The Participation theme provided information and guidance to researchers across CP-Achieve on how to study and assess participation

## Key achievements



**Co-designed a participation survey** with young adults with cerebral palsy, focusing on life areas they identified as important to study



**Co-produced a journal article** for a special edition of *Childhood*, sharing insights and learnings from working together as co-researchers



**Consumer Advisor Rohan Symonds was awarded a Churchill Fellowship** to travel to the United States, where he met with Project TEAM collaborators to inform the program's adaptation for the Australian context



**Collaborated with international colleagues to deliver the 4th International Participation Conference** in Singapore (2024), showcasing global perspectives on inclusion in action

# Theme: Developing a Specialist Workforce

## What we did

CP-Achieve recognised the critical need for workforce development and, over its five years of funding, prioritised building research capacity in adolescent and young adult health for people with cerebral palsy.

As part of this theme, we successfully engaged both emerging and established researchers by awarding postdoctoral and doctoral positions, fostering a vibrant community of research and collaboration. Many of these early-career researchers, supported through supervision and mentorship by CP-Achieve investigators, subsequently secured competitive grants and scholarships. This growth in research capacity saw a strong focus on knowledge translation, with team members actively supported to share their insights through high-quality publications, presentations, and other impactful outputs. To further support dissemination, CP-Achieve travel scholarships were awarded through a competitive selection process to doctoral and postdoctoral researchers, as well as consumers.

These capacity-building activities were further supported through targeted education and training delivered via webinars and symposia reinforcing CP-Achieve's commitment to learning, development, and leadership.

Through this theme CP-Achieve has made a significant contribution to narrowing the gap between research and practice

## Key achievements



### 6 Postdoctoral Fellows

funded in physical health, mental health, and lifestyle interventions research



Postdoctoral Fellows were supported to develop independent research programs securing over **\$347,000 in competitive grants**



**4 doctoral scholarships awarded**- 3 completed, 1 submitted



Established a **PhD and Early Career Researcher support network** to foster collaboration, mentoring, and professional development



**43 webinars** delivered to a combined audience of over 1000



**23 international and national travel scholarships** awarded enabling doctoral and postdoctoral researchers, and consumers to present research and collaborate globally



Hosted **3 biannual symposia** in partnership with the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDMD), attracting over 650 total attendance.

# Theme: Health Economics

## What we did

Health economics was embedded as a key theme within CP-Achieve to inform evidence-based decision-making through analysis of costs and cost-effectiveness, and to demonstrate the broader health and economic impact of program priorities.

Building on expertise developed in the preceding CRE-Cerebral Palsy program, the health economics stream aimed to assess the value and long-term impact of interventions for individuals with cerebral palsy across the lifespan. A PhD scholar with specialist expertise in quality-of-life measurement contributed significantly to this work, including through a systematic review of the available economic evidence for cerebral palsy interventions.

This integrated health economics approach provided important insight into the value, equity, and sustainability of cerebral palsy related interventions and services in the Australian context

The health economics theme included predictive modelling of selected interventions to estimate potential cost savings for families, health and welfare sectors, and productivity; improvements in health outcomes; and equity impacts across stakeholders. Additional methods included causation analysis such as logistic regression in discrete choice modelling, full economic evaluations alongside clinical trials, and desktop modelling where trial data was not available. The work also involved assessments of the Health Utilities Index (HUI-3), the performance of the NDIS and Medicare for people with cerebral palsy, and the impact of different funding models. Scenario modelling and literature reviews supported long-term planning and policy relevance.

## Key achievements



Provided **expert advice** to the CP-Achieve Steering Committee, research programs, and projects



Supported **2 data linkage projects**



Supervised and supported **completion of a PhD** on outcome measurement



Played a key role in the **delivery of multiple research projects**



Contributed to **2 successful grant applications**



Contributed to **multiple grant applications**

# Theme: Consumer Involvement

We worked with consumers to ensure research and outcomes aligned with the real needs of young people with cerebral palsy and their families

## Key achievements



Involved and supported **50 consumers as investigators and advisors** in CP-Achieve research



Established **4 consumer advisory groups** to guide and contribute to projects



Employed a **Consumer Involvement Knowledge Translation Fellowship**



**Contributed expertise** to NHMRC's Consumer Involvement Statement review



Instigated **ongoing evaluation** of CP-Achieve consumer involvement



**Co-developed** CP-Achieve's **transition process** with consumers



**Supported consumers to co-present and lead panels** at conferences



Developed **2 key resources to guide researchers** in consumer involvement

## What we did

CP-Achieve embedded consumer involvement across all aspects of our work, valuing the unique expertise that young people with cerebral palsy and their families bring through lived experience. Consumers collaborated with us as research partners and advisors, in advisory groups and project teams across the program.

Young people with cerebral palsy and parents were supported and mentored to take on roles as co-investigators, collaborators, and consultants throughout the research cycle. They were involved from research project inception to dissemination- guiding the identification of priority research questions, participant recruitment, ensuring outcomes were important to consumers, developing informative study materials, and in knowledge translation to clinicians, policymakers, and the community.

To strengthen and sustain this work, we employed consumer coordinators with lived experience of cerebral palsy and disability who fostered connection and collaboration between consumers and research teams.

We equipped researchers to meaningfully engage with consumers by providing education, resources, funding and ongoing support to build effective partnerships throughout the research process.

## Advisory Groups

Alongside the involvement of consumers in individual research projects, four advisory groups had a substantial impact on the work of CP-Achieve. Consumer involvement is often limited by a lack of funding at the earliest stages of research, particularly during the development of research priorities, directions, and questions. CP-Achieve enabled meaningful engagement throughout the entire research lifecycle.

By establishing advisory groups, CP-Achieve was able to engage with consumers from the outset, ensuring their voices and expertise informed the foundation and direction of the research

### CP-Voice

Adolescent advisory group comprising of 6 young people with cerebral palsy aged 10-18 years. **Main achievement:** Members informed the early stages of projects and tested data collection methods. They built skills and confidence to take their expertise and research involvement to the next level, including new roles in advocacy, co-research, and leadership.

### CP-Unite

CP-Achieve's flagship advisory group of 7 young adults with cerebral palsy aged 18-30 years. **Main achievement:** CP-Unite was instrumental in driving the participation theme by defining life situations which were meaningful to young people with cerebral palsy. Members progressed from guiding CP-Achieve to taking on formal roles in research and advocacy beyond the CRE, applying their lived experience and insights in new professional settings.

### Parent Advisory Group

Consisted of 13 parents of young people with a range of presentations of cerebral palsy. **Main achievement:** Members helped align CP-Achieve's research focus with the needs of families of young people with cerebral palsy. Their insights led to more inclusive, relevant and impactful research. The collaboration between parents and researchers also established parents as co-creators of knowledge.

### One Group Our Voice

Group of 5 people with cerebral palsy who use augmentative and alternative communication (AAC). **Main achievement:** A framework and toolkit to support researchers to involve AAC users as participants and partners in research, a publication describing the development of the framework, and several webinars and conference presentations.

## Consumer Involvement Projects

Several CP-Achieve projects specifically focused on strengthening consumer involvement and evaluating the impact of our involvement practices. These initiatives examined how consumer input shaped research design, implementation, and outcomes, and provided valuable insights into what constitutes meaningful and impactful involvement.

### Consumer involvement in CP-Achieve research: A mixed methods approach to evaluating multiple perspectives

**Aim:** To evaluate consumer involvement across all levels of CP-Achieve over its lifespan by capturing perspectives from consumers, researchers, coordinators, and leadership. This research examined processes, authenticity, impact, and unintended outcomes to generate evidence that improves meaningful involvement in cerebral palsy research and informs best practice reporting **Status:** Ongoing. **Outcome:** An understanding of the process, authenticity and impact of consumer involvement; recommendations for future involvement of people with disability in research **Expected impact:** Evidence to provide information for the field regarding effective processes, strategies to enhance authenticity and means of harnessing impact of consumer involvement in disability research.

### Involvement of people with complex communication needs as consumer research partners

**Aim:** To increase involvement of people with cerebral palsy and complex communication needs in CP-Achieve and

more broadly **Status:** Complete.

**Outcome:** Secured funding from State Trustees Foundation Australia. Established One Group Our Voice who provided input to research projects. Collaborative development of a framework and a practical toolkit to support researchers to involve people who use AAC as research participants and consumer research partners **Impact:** By increasing researchers' capacity to meaningfully involve people who use AAC in research, the voices of AAC users will be heard, ensuring that studies address priorities that matter to their health and well-being and ultimately optimise outcomes for AAC users.

Project findings informed improvements to CP-Achieve's approach and contributed to broader knowledge on best practice in consumer involvement in health and disability research

# Consumer Involvement Projects

## Evaluation of mentor program for young adult research partners

**Aim:** To explore the mentor program from the perspectives of young people with cerebral palsy and their mentors to identify strengths, areas for improvement, and inform ongoing implementation while contributing to evidence on mentoring in this population **Status:** Complete. **Outcome:** Understanding the perspectives and experiences of mentors and mentees who participated in CP-Achieve’s mentorship program **Impact:** The study provided recommendations to inform revision and development of CP-Achieve’s and similar mentor programs to optimise the experience for mentors and mentees, and the impact that young people with cerebral palsy may have in their roles as consumer research partners.

## Structured transition process for consumers at the conclusion of CP-Achieve

**Aim:** To support consumers with transitioning their involvement in CP-Achieve research to other cerebral palsy or disability research involving consumer participation **Status:** Complete. **Outcome:** A structured process was co-developed and implemented to support consumers to transition at the end of CP-Achieve **Impact:** Formal acknowledgment of individual consumers’ contributions and summary of achievements, and identification of opportunities for consumers’ continued involvement in research and advocacy.



*Freya Munzel, CP-Achieve Consumer Partner, and Dr Stacey Cleary, CP-Achieve Postdoctoral Research Fellow, at the CP-Achieve and AusACPDM 2025 Cerebral Palsy Symposium: Progress and Possibilities, Melbourne, Australia*



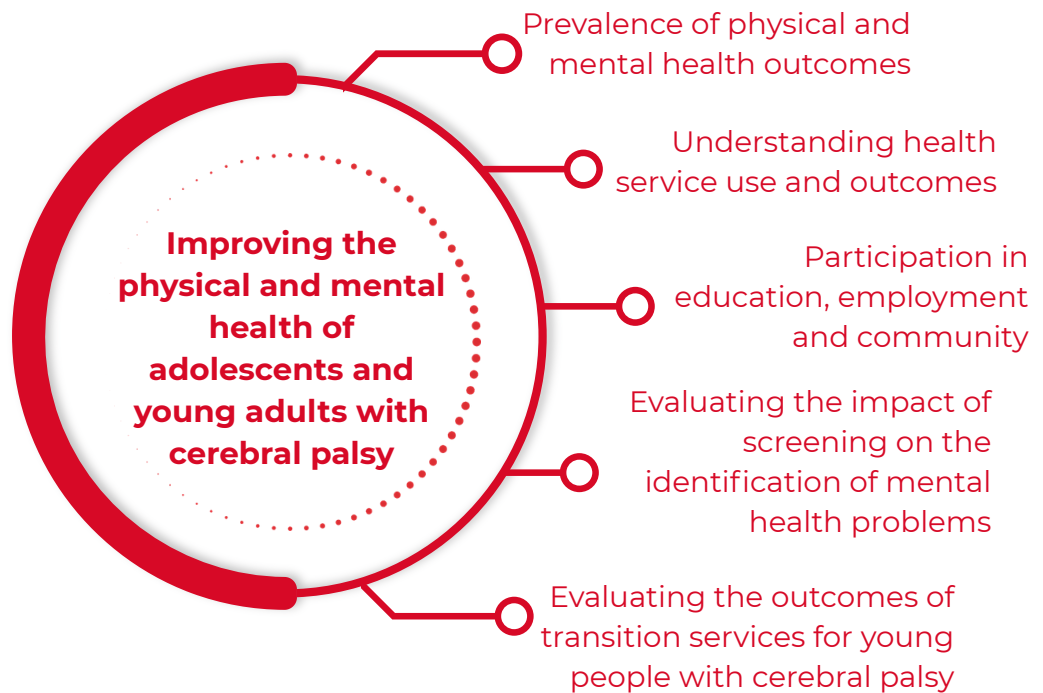
*Photograph submitted by Kyra Culloton, for the AusACPDM and CP-Achieve 2022 Lived Experience Photo Exhibition*

# CP-Achieve Programs

CP-Achieve was built around two core research programs, forming the foundation for all project activity and enabling a comprehensive and coordinated approach to improving outcomes for young people with cerebral palsy.

# Program 1

This program focused on improving the physical and mental health of adolescents and young adults with cerebral palsy. It aimed to quantify the health impact of cerebral palsy and associated service use, and to generate evidence to improve healthcare access, treatment, and outcomes.



# Program 2

The second program aimed at building supportive family, community, and health service environments that enable young people with cerebral palsy to participate fully in the life situations that matter to them.



# Program 1 Overview

## Improving the physical and mental health of adolescents and young adults with cerebral palsy

### Overview

Program 1 generated critical insights into the physical and mental health needs of adolescents and young adults with cerebral palsy.

Through co-designed research, national surveys, and data linkages, the program explored complex relationships between pain, fatigue, sleep, anxiety, and depression, as well as service use, participation, and care transitions.

It identified key service gaps and developed practical tools to improve screening, assessment, and access to care informing evidence-based improvements in clinical practice, service design, and policy.

### Key Achievements

#### Prevalence of physical and mental health outcomes

- National surveys confirmed high rates of pain, fatigue, anxiety, and depression across all functional levels.
- Tools developed for better chronic pain assessment.
- Important communication needs identified for adolescents using AAC, related to sexual health.

#### Understanding health service use and outcomes

- Documented GP and hospital access by people with cerebral palsy.
- Identified disparities in disability funding (age and location).
- Ongoing data linkage will enhance understanding of service patterns, costs, and gaps in preventive care.
- Systematic reviews highlighted factors that influence access to primary care.

#### Participation in education, employment and community

- National survey highlighted key environmental barriers limiting participation in work, education, and social life.
- Emphasised the importance of knowledgeable support and accessible opportunities.

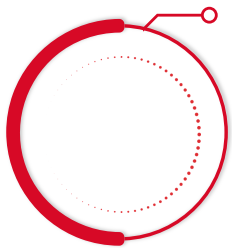
#### Evaluating the impact of screening on the identification of mental health problems

- Commenced the validation process for screening tools to identify mental health needs effectively.
- Showed telehealth mindfulness reduces stress and improves emotional wellbeing.
- Developing assessment methods for mental health in individuals with complex communication needs.

#### Evaluating the outcomes of transition services for young people with cerebral palsy

- Identified family-reported barriers to independent living transitions.
- Established statewide transition networks and practical tools to improve transition.

# Program 1 Projects



## Prevalence of physical and mental health problems

*This research area provided population-based data on key health issues —pain, insomnia, fatigue, and mental health problems*

### Physical and Mental Health Survey

**Lead:** Dr Sarah Giles and Dr Carlee Holmes

**Status:** Complete. **Aim:** Through a series of linked national surveys, we aimed to describe the physical and mental health of young people with cerebral palsy and to explore the associations between pain, fatigue, sleep, anxiety, and depression.

**Outcomes:** 72 people with cerebral palsy aged between 10-31 years, 55.6% female with representation across all levels of the cerebral palsy functional classification systems responded to surveys regarding pain, fatigue, sleep, anxiety and depression. Strong associations were identified between most outcomes ( $r \geq 0.50$ ). **Impact:** The study validated the experiences of pain, fatigue, sleep disturbance, anxiety, and depression in young people with cerebral palsy. It contributed new evidence about the relationships between physical and mental health in young people with cerebral palsy, with the often-neglected inclusion of people with more severe and complex disability who require proxy reporting.

### Development of a Core Outcome Set to assess chronic pain for children and young people with cerebral palsy using a biopsychosocial approach (PhD)

**Lead:** Nadine Smith **Status:** Complete.

**Aim:** The primary aim of this research was to develop a Core Outcome Set of chronic pain assessment tools that capture the psychosocial impacts of chronic pain in individuals with cerebral palsy. A key objective was to ensure that the recommended tools are accessible and appropriate for use across the wide range of communication, cognitive, and motor abilities within this population.

**Outcomes:** This research led to the development of a Core Outcome Set for assessing the impact of chronic pain in children and young people with cerebral palsy. It identified valid and reliable tools that measure the emotional and functional interference of pain, and evaluated their feasibility across a range of communication, cognitive, and motor abilities. A decision tree was also developed to guide clinicians and researchers in selecting the most appropriate tools based on individual abilities. **Impact:** This program of research has developed a Core Outcome Set that can improve the identification and assessment of chronic pain, underpinned by the criterion standard biopsychosocial model. Improved assessment of chronic pain will facilitate referral to best practice multidisciplinary interventions for all people with cerebral palsy, regardless of their communication, cognitive or motor abilities.

## Conversations about sexuality: Experiences of adolescents with cerebral palsy and complex communication needs (CCN) and their guardians (PhD)

**Lead:** Megan Walsh **Status:** Ongoing.

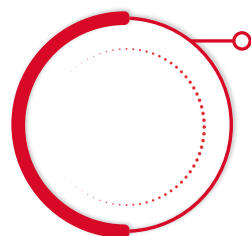
**Aim:** This program of research aimed to (i) develop a shared understanding between adolescents with cerebral palsy who use augmentative and alternative communication (AAC) and their parents or guardians about how these adolescents engage in conversations and interactions around sexuality, and (ii) to work collaboratively with participants to share these insights with other stakeholders.

**Outcomes:** Five adolescents engaged in participatory research which included interviews and co-design of knowledge translation artefacts. Twelve parents were interviewed, followed by a small focus group for participatory analysis. Findings identified both adolescent priorities for conversations about sexuality as well as key supports required. **Impact:** This project has already demonstrated positive impacts for the individual participants' communication about sexuality, for their communication supporters, for clinicians and for researchers. A co-designed knowledge translation plan is driving further knowledge translation with AAC users, clinicians and researchers. This includes three articles co-authored with consumer research partners.

## Understanding cognitive fatigue in people with cerebral palsy

**Lead:** Dr Iain Dutia **Status:** Ongoing. **Aim:** To estimate the prevalence of cognitive fatigue in people with cerebral palsy, explore its associations with physical fatigue, pain and mood, and understand its impact on daily life through interviews with individuals and carers.

**Outcomes:** The study is generating quantitative data via survey and rich qualitative data via interviews. It is producing novel findings about the experience and correlates of cognitive fatigue in this population. **Impact:** Co-designed with people with cerebral palsy, this research will generate practical recommendations for clinicians to identify and support individuals experiencing cognitive fatigue. Findings will inform assessment practices and guide future service design.



## Understanding health service use and outcomes

*This research area examined whether patterns of health service use among young people with cerebral palsy reflected their needs and differed from those without cerebral palsy. This data and care perceptions revealed barriers and highlighted ways to reduce hospitalisations and improve care access and integration for people with cerebral palsy*

## Understanding health service use and outcomes

**Lead:** Dr Sarah Giles and Dr Carlee Holmes **Status:** Complete. **Aim:** The aim of the Understanding Survey was to establish an accurate and up-to-date database of the demographic and clinical characteristics of young people with cerebral palsy who consented to be contacted for future CP-Achieve research. **Outcomes:** A total of 182 young people with cerebral palsy were successfully surveyed, and a comprehensive report was completed in February 2024. The Understanding Survey

created a robust database of demographic and clinical information, laying the groundwork for ongoing participant engagement and guiding future CP-Achieve activities. **Impact:** The project provided key demographic and cerebral palsy descriptor information critical for identifying participants for future studies and understanding adaptations needed to enable young people's participation. Linkage with the Participation and Mental and Physical Health surveys reduced participant burden by requiring these questions to be completed only once.

### NPS MedicineWise Data- Understanding General Practitioner use

**Lead:** Professor Dinah Reddihough  
**Status:** Complete. **Aim:** The primary aim of this study was to understand the frequency and reasons for general practitioner attendance in a cohort of people with cerebral palsy using MedicineInsight, a national general practice data program developed by NPS MedicineWise and transitioned to the custodianship of the Australian Commission on Safety and Quality in Health Care in 2023. **Outcomes:** People with cerebral palsy consulted general practitioners on average 19 times over a 5-year period. Visits were for diverse conditions. They were prescribed multiple medications, including analgesics, anti-epileptics, antipsychotics, anxiolytics, hypnotics, sedatives, centrally acting muscle relaxants, and laxatives. **Impact:** This is the first study to describe the use of general practitioner services by people with cerebral palsy across Australia. The extensive use of some drugs including opiates, requires further exploration. Important preventive screening measures

seem to be less regularly undertaken than in the population without disability.

### Australian Institute of Health and Welfare databases and the Victorian Cerebral Palsy Register

**Lead:** Professor Dinah Reddihough  
**Status:** Ongoing. **Aim:** Our aims are to provide an understanding of health service use, expenditure and welfare support payments, in adolescents and adults with cerebral palsy aged 10-50 years, by linking Australian Institute of Health and Welfare administrative datasets with the Victorian Cerebral Palsy Register. **Outcomes:** There have been substantial delays (approximately 3.5 years) in receiving the linkage. The data will be made available to us early in 2026, and we hope to complete this project within the next 1-2 years. **Estimated Impact:** This comprehensive linked data asset will enable us to understand how people with cerebral palsy use health services. Data will be generated about potentially avoidable hospital admissions and emergency department presentations to identify issues that could be addressed in primary care. An economic analysis will be applied to identify cost drivers and cost burdens.

### Interrogation of NDIA dashboards (NDIS service environment)

**Lead:** Professor Prue Morgan **Status:** Complete. **Aim:** Explored NDIS plan payments and support category by people with CP using publicly accessible NDIS data. A descriptive analysis was undertaken using observational statistics and variable comparisons to explore lifespan plan characteristics (core supports, capacity building and capital supports proportions) and payments between

different age groupings and geographical regions. **Outcomes:** 17,575 people with CP were NDIS participants, average plan payments \$138,000/year, increasing with age. Most funding was allocated to core supports (~\$103,000 Pa) compared to capacity building (~\$40,000 Pa) and capital supports (~\$11,000 Pa). There were large differences in plan payments between metropolitan and regional, likely influenced by personal and service availability factors. **Impact:** This research highlights gaps in NDIS funding priorities, revealing larger plan payments for older people with cerebral palsy coupled with insufficient support for employment and lifelong learning, despite these being key scheme priorities. Regional disparities in payments emphasise the need for further research to promote equitable access and improved outcomes nationwide.

### NDIA unit record data project

**Lead:** Professor Christine Imms

**Status:** Ongoing. **Aim:** This project aimed to create a profile of use and impacts of the National Disability Insurance Scheme (NDIS) on people with cerebral palsy. The objective was to characterise those who access and use NDIS funding to inform future cerebral palsy advocacy, practice and research. **Outcomes:** Findings demonstrated that (i) people with cerebral palsy are more likely (than other disabilities) to be accepted, but there is associated administrative burden; (ii) the number of people with cerebral palsy in the NDIS is stabilising at around 23,000; (iii) remoteness is associated with reduced plan size and spending. **Impact:** Detailed information about the NDIS plan size and spending of people with cerebral palsy across the life course, can be used to inform advocacy efforts, and to track changes over time as NDIS reforms are implemented.

### Exploring the profile of general practice access and interventions among adults with cerebral palsy: A systematic review

**Lead:** Professor Prue Morgan **Status:**

Complete. **Aim:** This review aimed to investigate characteristics and utilisation of general practitioner (GP) access by adults with cerebral palsy. Secondary aims included exploring reasons prompting access, identifying interventions provided, and personal features affecting access.

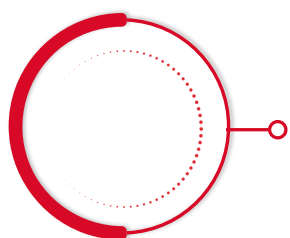
**Outcomes:** Fifteen studies were included describing GP access; 6231 adults with cerebral palsy. Proportion annually accessing GP was 78%. GP access frequency ranged 1.76 to 11.7 visits/year, increasing with age and disability severity. Comorbid intellectual disability and pain increased attendance. Limited data was available reporting healthcare needs and no interventions were described. **Impact:** This research identified that advancing age, greater disability, comorbid intellectual disability, and pain increase GP visits among adults with cerebral palsy. Understanding reasons for primary care use and interventions will improve lifespan care. Outcomes will support the subsequent development of a checklist for both GPs and consumers.

### Health service utilisation by people ageing with cerebral palsy

**Lead:** Professor Prue Morgan **Status:**

Complete. **Aim:** This study aimed to identify determinants associated with how individuals with cerebral palsy access hospital-based health services. **Outcomes:** 284 individuals, mean age 40.6 years, were identified. Health service encounters ranged 1-163 times in 5 years. Living in supported accommodation increased likelihood of accessing any health service

including emergency care. Younger adults were less likely to access any health service compared to children; being older increased likelihood of inpatient admission. **Impact:** This research showed that living in supported accommodation increases health service access, with older adults more likely to use inpatient care and younger adults less likely to access any services. It highlights the need for deeper understanding of how individual factors like location, disability complexity, and life stage influence service use to improve care access.



## Participation in education, employment and community

*This research area focused on exploring changes within individuals over time and identifying key differences in outcomes based on age and geographic location*

### Participation survey

**Lead:** Professor Christine Imms  
**Status:** Ongoing. **Aim:** This survey explored the participation patterns of, and environmental influences on, participation of people with CP (aged 10-30 years). Information was sought about participation in the key life areas identified by young people with cerebral palsy as important: home life, relationships, education, employment, leisure, physical activity and community, and health care. **Outcomes:** Overall, 79 people took part with representation from each level of the functional classification systems. Participation attendance varied by life situation. When attending, involvement was typically

rated as 'mostly involved'. High proportions (50 – 89%) indicated a need for environmental accommodations to support participation. While acceptability of supports was often rated low, there was also a low percentage desiring change.

**Impact:** The survey findings identify environmental and contextual factors that should be targeted for change to improve participation for people with cerebral palsy. For example, supporting healthcare attendance requires more professionals knowledgeable about cerebral palsy; employment needs suitable work opportunities; relationships benefit from chances to meet people; and community participation depends on staff awareness. Attitudes of others and expectations of participation were important barriers to participation in most life situations.



## Evaluating the impact of screening on the identification of mental health problems

*This research area focused on identifying mental health problems in young people with cerebral palsy, and using data to build a clearer understanding of treatment and service needs*

### Improving the assessment of anxiety and depression in young people with cerebral palsy: Investigating screening procedures and understanding experiences of seeking help

**Lead:** Associate Professor Melissa Mulraney **Status:** Ongoing. **Aim:** This project aims to assess the acceptability and validity of two measures for anxiety

and depression in young people with cerebral palsy and explore their and their parents' experiences when seeking mental health support. **Expected Outcomes:**

Upon completion of the project, we will have an evidence base indicating which measures are more reliable and valid for identifying mental health issues in young people with cerebral palsy. Our research will also identify specific gaps in mental health services and school support for young people with cerebral palsy.

**Estimated Impact:** The evidence generated by this study will support future grant applications to scale effective interventions or develop national programs aimed at improving mental health care for individuals with cerebral palsy. Findings will also inform healthcare and education policies, advocating for systemic changes to better meet their mental health needs.

## Randomised control trial of mindfulness

**Lead:** Dr Ingrid Honan **Status:** Complete.

**Aim:** The aims of this randomised control trial were to investigate whether a modified telehealth Mindfulness Based Stress Reduction (MBSR) program could improve mindfulness and reduce depression, anxiety, and emotion regulation difficulties among adults with cerebral palsy with elevated anxiety and/or emotional regulation difficulties.

**Outcomes:** The program was well-received and helped participants feel less stressed and more in control of their emotions. While overall mindfulness didn't change significantly between the two groups, participants who received the MBSR intervention showed improved Cognitive and Affective Mindfulness Scale-R scores between baseline and

immediately post intervention and between baseline and after delay post intervention; improved mean scores for Depression and Stress subscales between baseline and immediately post intervention; and improved Difficulties in Emotion Regulation Scores between baseline and immediately post intervention and between baseline and after delay post intervention. The results suggest this approach is practical and helpful for adults with cerebral palsy.

**Impact:** Whilst this study found no significant between-group difference for the primary outcome of mindfulness knowledge, the MBSR program was successfully modified for adults with cerebral palsy and was effective in improving depression, stress, and emotion regulation. Qualitative results show that whilst there are aspects of the program that can be improved, participants enjoyed the program and valued accessing a variety of mindfulness techniques.

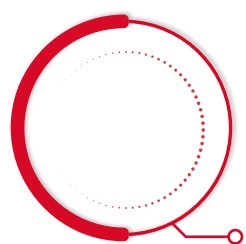
## Developing an approach to assessing the mental health of young people with complex communication needs (PhD)

**Lead:** Jacinta Pennacchia **Status:**

Complete. **Aim:** Driven by the belief that all people should have equitable access to services to address their mental health needs, the aim of this PhD was to develop an approach to identifying mental health concerns in young people with complex communication needs. **Outcomes:** The outcomes of this PhD include: (i) a systematic review that identified a significant lack of validated instruments for measuring wellbeing in individuals with complex communication needs; (ii) a mixed methods study exploring current practices and future requirements of practitioners assessing mental health in

this population; and (iii) a qualitative study capturing the lived experiences of AAC users regarding their mental health experiences. **Impact:** This PhD integrates knowledge from existing measures, the workforce, and AAC-users and their families to shape mental health assessment approaches.

Effective assessment requires multidisciplinary collaboration, access to appropriate tools, sufficient time, and a shared language to ensure clear communication and better support for young people with complex communication needs.



## Evaluating the outcomes of transition services for young people with cerebral palsy

*This research area examined whether transition outcomes for young people reflected the type of supports and pathways used during the move from paediatrics to adult care. Comparing these outcomes helped identify requirements for effective transition support*

### Transition to independent living

**Lead:** Dr Lyndal Hickey **Status:** Ongoing.  
**Aim:** To explore adolescent and young adults (AYA) with cerebral palsy and family member perspectives on the transition to independent living. **Outcomes:** Family members told us about their perspectives on the transition to independent living and the barriers and enablers within family, service systems and communities that impact on this process for the young

person with cerebral palsy. Unfortunately, we had a low number of AYA participate and were unable to report on their perspectives in this study. However, we will revisit and centre the AYA experience with a PhD study. **Estimated Impact:** Two forthcoming papers provide evidence on the challenges and supports families face during the transition to independent living for young people with cerebral palsy, with potential to inform future policy and service design. The research also led to a Melbourne Disability Institute PhD scholarship exploring autonomy, identity, and everyday independence.

### Transition and services for adults including care pathways

**Lead:** Evelyn Culnane **Status:** Ongoing.  
**Aim:** To develop pathways and resources for adults with CP transitioning from paediatric to adult care and for clinicians working with them. **Outcomes:** In collaboration with Western Victoria PHN, four cerebral palsy HealthPathways were published to guide care across the lifespan. Statewide paediatric and adult rehabilitation meetings were convened, and surveys of both adult and paediatric rehabilitation physicians were completed. Checklists were also developed to support care planning for adults with cerebral palsy. **Impact:** This work has improved statewide coordination of care for individuals with cerebral palsy by strengthening hospital networks and fostering clinical collaboration. Cerebral palsy-specific HealthPathways, national physician surveys, and practical tools such as care planning checklists are driving more informed, consistent, and person-centred care across services and the lifespan.

# Program 2 Overview

## Building supportive family, community, and health service environments

### Overview

This program advanced inclusion and participation outcomes for children and adults with complex disability, particularly cerebral palsy.

Through co-designed research, it developed and tested physical activity and participation-focused interventions, adapted global evidence for local contexts, and deepened our understanding of lived experience.

The work strengthened inclusive practice across health, disability, and community service, shaping clinical care, informing policy, and building stronger pathways from rehabilitation to everyday life.

### Key Achievements

#### Exercise in Complex Disability

- Developed and tested home-based and inclusive cycling and gym programs for people with varied mobility.
- Demonstrated feasibility, safety, and benefits for wellbeing.
- Informed program design, clinical education, and broader adoption of adapted exercise approaches.

#### Understanding the needs and perspectives of people with cerebral palsy and their families

- Explored young adults' experiences, highlighting aspirations and systemic barriers.
- Identified misalignment between NDIS funding and young people with cerebral palsy's goals.

#### Creating pathways from rehabilitation to recreation

- Investigated young adults' experiences in community gyms, identifying supports needed to increase inclusion and sustainability of physical activity.
- Supported increased access to physical activity options through collaboration with community, clinical, and consumer stakeholders.

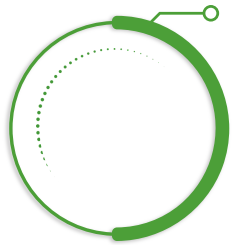
#### Translating available participation-focused intervention evidence to the Australian context

- Adapted and tested global interventions (e.g. PREP, Project TEAM) for young people with complex disability.
- Co-developed tools, a Young Adult PREP Supplement, and consumer involvement evaluation methods.
- Strengthened evidence for person-centred, participation-focused practice across sectors.

#### Adapting an evidence-based lifestyle program

- Co-designed a digital health literacy module (Your Health) with young adults with cerebral palsy, addressing a key gap in autonomy and healthcare engagement.
- Achieved high usability and satisfaction, offering proof-of-concept for inclusive digital tools.

# Program 2 Projects



## Exercise in complex disability

*This research area advanced inclusive, community-based exercise interventions for individuals with complex disabilities, developing safe, accessible, and sustainable protocols. The work produced training resources to support wider adoption and demonstrated viable funding pathways to ensure long-term sustainability and improved health outcomes*

## Cycling resources and programs in disability (PhD)

**Lead:** John Carey **Status:** Ongoing. **Aim:** To develop and pilot online cycling resources with young people with disability and their support networks by surveying current adaptive cycling practices, feasibility testing the CHAIN provider training program, and co-designing, implementing, and evaluating a novel cycling program (CycLink). **Outcomes:** A publication was produced outlining diverse training approaches, participation barriers and enablers, and practice gaps. These findings guided refinement of the CHAIN online training program. Resources were also created for adapted Experience-Co-design methods, and principles for the CycLink program were established, supporting successful NHMRC grant acquisition. **Impact:** This work enhanced understanding of young people's and

parents' experiences learning to cycle with a disability and identified effective strategies to connect youth with local cycling opportunities. The project also clarified providers' learning needs for knowledge translation and developed an inclusive, adapted methodology for co-design processes.

## Adapted bike program (PhD)

**Lead:** Abby Thevarajah **Status:** Ongoing. **Aim:** This doctoral research aims to build evidence on the impact of adapted bike riding on participation outcomes for children with disabilities (aged 4–18) and their families, to inform future clinical research and practice. **Outcomes:** The systematic review identified limited high-quality evidence and emphasised the need for participation-focused research. Building on this, the qualitative study revealed strong support from children, families, and therapists, offering key recommendations to enhance program delivery. Currently, a feasibility study is examining implementation, acceptability, and early impacts on participation and skill development. **Impact:** This work is expected to influence clinical practice, guide future research, and inform service design to enhance inclusion and participation through adapted bike riding.

## Exercise interventions for those with complex cerebral palsy (PhD)

**Lead:** James Czencz **Status:** Complete. **Aim:** This project aimed to evaluate exercise interventions to improve activity,

participation, and quality of life for adults with complex cerebral palsy, particularly those who use wheelchairs and live in regional areas. It addressed evidence gaps through a systematic review, qualitative study, and feasibility trial of a community-based gym program (*FitSkills*). **Outcomes:** This project found preliminary evidence that exercise interventions could be acceptable, practical, and beneficial for adults with complex cerebral palsy, particularly those using wheelchairs in regional areas. It identified key adaptations, highlighted the importance of participation-focused outcomes, and demonstrated the feasibility of community-based programs like *FitSkills* to enhance inclusion and quality of life.

**Impact:** This work has advanced understanding of exercise for adults with complex cerebral palsy, influenced inclusive program design, and informed policy for community inclusion events (inclusive gym programs and beach days). It has led to the development of university curricula on adults with cerebral palsy at two institutions (UNSW, CQU), promoting workforce readiness and driving community-based initiatives that improve participation, quality of life, and access.

### Home-based motorised cycling in non-ambulant adults with cerebral palsy

**Lead:** Carlee Holmes **Status:** Ongoing.

**Aim:** To investigate the effects of physical activity on cardiometabolic biomarkers in non-ambulant adults with cerebral palsy. To explore the impact of motorised cycling on pain, fatigue, sleep and leg function.

**Expected Outcomes:** To date, 14 participants have been recruited, and data collection is underway. The study is generating important insights into how motorised cycling may support overall health and wellbeing in non-ambulant

adults with cerebral palsy, with a focus on both physiological and functional outcomes. **Estimated Impact:** It is hypothesised that motorised cycling will positively influence environmental and personal factors and logistical barriers contributing to decreased participation in physical activities and increased sedentary behaviours for those with profound disability and mobility issues.

### Community based exercise for people with complex disability (scoping review)

**Lead:** Professor Prue Morgan **Status:** Complete. **Aim:** To identify implementation strategies and safety outcomes (adverse events) of community-based physical activity interventions for adolescents and adults with complex cerebral palsy. **Outcomes:** Seventeen studies were included, with 160 of 262 participants classified at GMFCS levels IV or V. Community settings ranged from schools, and homes to gymnasias and swimming pools. Common implementation strategies involved pre-exercise screening, use of adapted equipment, familiarisation sessions, supervision, physical assistance, and physiological monitoring. Reported adverse events were mostly non-serious, expected, and related; serious events were rare. **Impact:** This review demonstrates that community-based exercise programs can be safely undertaken by individuals with complex cerebral palsy. Among participants classified at GMFCS levels IV or V, post-exercise pain and fatigue were uncommon, and serious adverse events were infrequent when appropriate safety strategies were used. These findings support broader inclusion in physical activity and provide guidance for safer program design and policy development.

## Aquatic exercise for adolescents and adults with cerebral palsy: A scoping review

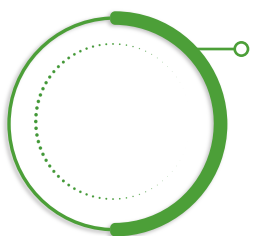
**Lead:** Isabel Huf/ Professor Prue Morgan  
**Status:** Complete. **Aim:** To identify characteristics of participants, intervention features and outcomes in studies examining aquatic exercise for adolescents and adults with cerebral palsy. **Outcomes:** Eleven studies were included, 66 participants in total. Three studies included participants with greater disability; four studies included participants >30 years. Aquatic program components were variable. Reporting of intensity, adverse events, and safety measures was poor. Participation outcomes were included in only three studies. No study formally gathered participant experiential data.  
**Impact:** Aquatic programs for individuals with cerebral palsy appear focused on younger people and those with mild to moderate disability. Poor reporting of program design has led to non-reproducible studies and inconsistent approaches to aquatic exercise for adolescents and adults with cerebral palsy. Participant, carer and clinician perspectives on aquatic programs remains unknown.

## Evidence-based lifestyle program (PhD)

**Lead:** Jackie Ding **Status:** Complete.  
**Aim:** To co-design and test a digital health literacy module, 'Your Health', with young adults with cerebral palsy and other stakeholders (families, healthcare professionals) to support informed participation in healthcare during young adulthood. **Outcomes:** Using an overarching Integrated Knowledge Translation framework, this three-stage project resulted in the creation of an online health literacy focused module that was developed with input from young adults with cerebral palsy, parents, and clinicians. Usability testing showed high engagement and satisfaction (SUS score: 80.2). The module filled a critical service gap. **Impact:** The module demonstrated proof-of-concept for co-designed, cerebral palsy-specific digital tools. It has since informed consumer engagement resources and is being disseminated as a pilot health literacy resource. The project contributed to a replicable model for inclusive health education development.

## Evidence-based lifestyle program (expanded suite of offerings)

**Lead:** Dr Stacey Cleary **Status:** Ongoing.  
**Aim:** Co-design of a series of lifestyle modules ('CP-Pathfinding') to enhance the knowledge and develop the skills of young adults with cerebral palsy, in key life areas. **Outcomes:** The pilot development of the online 'your health' and 'fitness for life' online modules are now complete. The website for fitness for life was launched at the end of August 2025. **Impact:** The successful co-design of these two pilot modules paves the way for development and implementation of full modules, across a range of key life areas. The data gathered and products created provide a



### Adapting an evidence-based lifestyle program to Australian context

*This research area focused on adapting effective lifestyle interventions for young Australians with cerebral palsy. Informed by consumer input, the projects promoted positive health behaviours, improved wellbeing, and service capacity*

basis for future community partner collaborations and funding applications.

### Health literacy in young adults (PhD)

**Lead:** Jackie Ding **Status:** Complete.

**Aim:** To synthesise available evidence on health literacy in adolescents and young adults with cerebral palsy and explore how health literacy influences healthcare engagement, autonomy, and quality of life outcomes. **Outcomes:** A mixed-methods systematic review found health literacy to be under-researched yet vital for participation and autonomy. The review identified specific needs for communication-accessible resources and cerebral palsy-specific content. The paper was selected as a 'Top 10 Article' by American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD).

**Impact:** This study positioned health literacy as a key, modifiable enabler of participation. It provided a strong evidence base for intervention development and received national and international recognition. Findings were cited widely and shaped future directions within CP-Achieve and the broader field.

### Understanding the needs and perspectives of people with cerebral palsy (PhD)

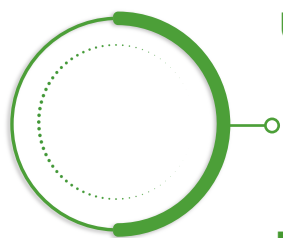
**Lead:** Jackie Ding **Status:** Complete.

**Aim:** To explore the lived experiences and participation perceptions of young adults with cerebral palsy across key life areas and understand how service systems and societal factors shape autonomy, identity, and inclusion during the transition into adulthood. **Outcomes:** The study identified strong aspirations for independence alongside pervasive barriers including ableism, inaccessible systems, and emotional labour. Findings highlighted the need for inclusive environments and identity-affirming supports. **Impact:** The study advanced understanding of participation for young adults with cerebral palsy and informed CP-Achieve frameworks. It contributed to national and international dialogue on disability inclusion and was cited in multiple scholarly articles. The publication also catalysed critical commentary and dissemination through webinars, podcasts, and author panels.

### NDIS capacity building goals (PhD)

**Lead:** Jackie Ding **Status:** Complete.

**Aim:** To examine the allocation and focus of NDIS Capacity Building goals for young adults with cerebral palsy using publicly available datasets and evaluate alignment with life stage priorities such as independence, decision-making, and life planning. **Outcomes:** The study found that while Capacity Building supports were widespread, they did not consistently align with the goals of young adults. Funding skewed toward daily living supports, with fewer goals related to employment or life skills, highlighting a potential misalignment between



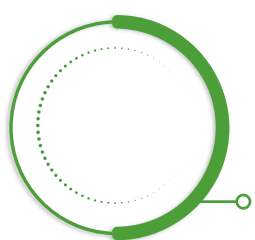
### Understanding the needs and perspectives of people with cerebral palsy and their families

*This research area addressed the factors influencing participation and independence among young people with cerebral palsy. Projects explored strategies to enhance enablers and reduce barriers across different living situations*

participant aspirations and funded supports. **Impact:** The study provided the first national-level analysis of NDIS Capacity Building funding for young adults with cerebral palsy. Findings informed CP-Achieve policy advocacy and were presented at major conferences. The results highlighted the need for reform to better reflect young people's participation goals in adulthood.

### Experiences of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review

**Lead:** Dr Stacey Cleary **Status:** Complete. **Aim:** This project aimed to synthesise components and implementation methods of internationally delivered lifestyle programs for people with cerebral palsy. **Outcomes:** Key findings from this review indicate that young people with cerebral palsy aspire to participate fully in adult life alongside their peers. Improved community accessibility, inclusion, and more supportive health environments would mean young people with cerebral palsy could more likely live the lives they choose. **Impact:** Results from this scoping review have shaped the development of the evidence-based lifestyle program, CP-Pathfinding. This review has only recently been published; we anticipate further impact and application with time and engagement.



### Creating pathways from rehabilitation to recreation

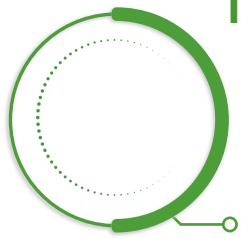
*Improving access to inclusive community exercise for young people with cerebral palsy was the focus of*

*this research area. Socio-ecological and implementation science approaches were used to identify strategies and address barriers in the transition from health services to community-based programs*

### Community based physical activity (PhD)

**Lead:** Georgia McKenzie **Status:** Complete. **Aim:** This project explored the factors that impact participation in community-based physical activity for young adults with cerebral palsy. Specifically, the project aimed to (i) Understand the factors impacting community based physical activity for young adults with cerebral palsy. (ii) Understand the experiences of young adults with cerebral palsy in community gyms. (iii) Identify strategies to support participation in community gyms. **Outcomes:** Collaboration with young adults with cerebral palsy occurred across all research stages, including design, data collection, analysis, and co-authorship on two peer-reviewed papers. We found that while the physical environment influenced gym participation for young adults with cerebral palsy, social factors like support, belonging, and enjoyment were most important. Support was often provided only after entry, highlighting a gap in access. Stronger partnerships between health professionals and gyms are needed to support transitions. **Impact:** This work influenced research and practice through a top-cited review, broad academic dissemination, and targeted knowledge translation. Engagement with clinical, community, and lived experience audiences via events, webinars, podcasts, and infographics supported greater awareness, practical application, and

accessibility of physical activity opportunities for young adults with cerebral palsy.



## Translating available participation-focused intervention evidence to the Australian context

*This research focused on adapting and implementing two evidence-based programs, Project-TEAM and PREP, to support participation for individuals with disabilities*

### PREP and CEval projects

**Lead:** Professor Christine Imms and Associate Professor Margaret Wallen

**Status:** Complete. **Aim:** This dual project aimed to (i) adapt and test the feasibility of the Pathways and Resources for Engagement and Participation intervention program for young adults with complex disability in Australia (PREP study); and (ii) evaluate the consumer involvement within the PREP study for authenticity and impact (CEval study).

**Outcomes:** PREP was successfully adapted for Australian young adults with complex disability and tested for feasibility with four young adults and their support people. Materials were co-designed to support implementation. The CEval project developed tools for consumer involvement evaluation and, in the PREP study, found high levels of authenticity and perceived impact of involvement.

**Impact:** Along with dissemination of study findings, a PREP-Young Adult Supplement

for the PREP manual was co-produced and is available on the CanChild website alongside the original PREP resources: manual and training designed by the primary authors. The CEval project produced new methods of evaluation. In addition, four occupational therapy honours students completed their research.

### Project TEAM

**Lead:** Professor Christine Imms **Status:** Complete. **Aim:** This project aimed to adapt and test the feasibility of the USA designed 'Project TEAM' intervention for use in the Australian context. TEAM stands for Teens making Environmental and Activity Modifications, and the intervention teaches young people how to identify and solve environmental barriers to participation. **Outcomes:** Project TEAM was successfully adapted to be more applicable in Australia and tested for feasibility in one Victorian service provider context. **Impact:** The adapted version of Project TEAM is in use in one provider location, two honours students have obtained their occupational therapy with honours degrees, and one consumer successfully obtained and completed a Churchill Fellowship.

# Translating Research into Practice and Education

CP-Achieve supported the translation of evidence-based approaches to improve the health and wellbeing of adolescents and young adults with cerebral palsy across Australia.

We built strong collaborations with young people with cerebral palsy and their families to share insights and co-develop practical solutions.

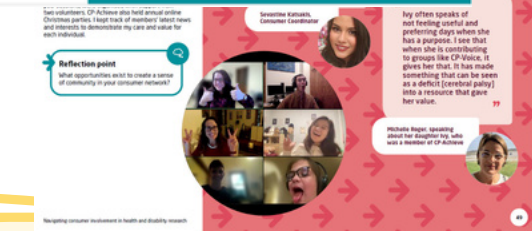
Knowledge translation was driven through targeted research and two dedicated fellowships. Together we produced accessible resources and implemented a multidisciplinary research program which aimed to improve participation by young people with cerebral palsy in meaningful life situations.



*Photograph submitted by Nofar Ben Itzhak for the AusACPDM and CP-Achieve 2024 Lived Experience Photo Exhibition*

## Navigating consumer involvement in health and disability research

Strategies and stories from CP-Achieve, a centre for research excellence in cerebral palsy



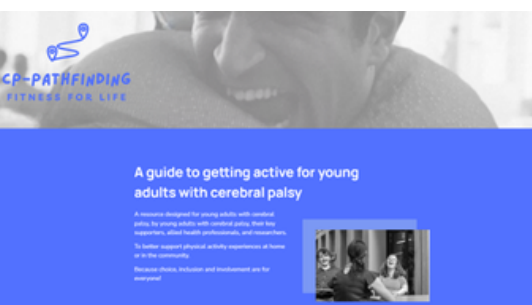
In recognition of this work, CP-Achieve was named a finalist in the inaugural Australian Consumer Partnerships in Research Awards 2025. We also commenced discussions for a partnership with the Western Australian Health Translation Network to co-develop education and were featured as a case study for the review of the NHMRC Statement on Consumer and Community Involvement in Health and Medical Research.

## Navigating Consumer Involvement in Health and Disability Research

Consumer involvement was central to CP-Achieve, with young people with cerebral palsy and their families actively engaged in all stages of the research. Together we developed ***Navigating Consumer Involvement in Health and Disability Research***. This resource shares strategies and stories about how CP-Achieve identified and supported consumers with disability and parents, created a small grants fund to encourage early involvement, equipped researchers to meaningfully engage with consumers, and demonstrated the influence of consumer involvement on researchers.

The resource features insights from five research projects, highlighting the roles, activities, costs, and impacts of consumer involvement. It also explores inclusive approaches for working with adolescents and young adults with disability, augmentative and alternative communication users, and parents – showcasing real-world strategies for making research accessible, safe, and authentic.

Access the resource by [clicking here](#)



The resources were launched in August 2025 and disseminated through the CP-Achieve webinar series, the Australian Physiotherapy Association, and the Kids+ Changemaker Conference. Impact will be measured through website visits, resource downloads

## Fitness for Life: Resources to build skills and knowledge for community and gym-based physical activity participation

Through co-design, we developed a suite of resources and an accessible website to build skills and knowledge for community and gym-based physical activity participation, including for people with high support needs. Young adults with cerebral palsy played a central role in creating content, photography, videography, and conducting interviews.

A case series study was also completed, highlighting real-world examples of community-based physical activity for adults with high support needs.

Access the website by [clicking here](#)

## Mental Health Toolkits

### **A Toolkit for Parents and Carers of people with Cerebral Palsy**

This mental health toolkit was designed for parents and carers of people with cerebral palsy to support early identification of potential mental health concerns. It offers practical guidance on recognising early signs and raising these concerns with a doctor and the person with cerebral palsy.

Access the toolkit by [clicking here](#)

### **A guide for young people with cerebral palsy to help recognise signs of mental health problems**

This toolkit is for people with cerebral palsy to help recognise early signs of mental health challenges. It offers clear examples of symptoms and practical tips for starting conversations with parents, carers, or health professionals.

Access the toolkit by [clicking here](#)



### **Inclusive Framework and Toolkit to include AAC users in research**

CP-Achieve researchers partnered with One Group Our Voice (OGOV), an advisory group of people with cerebral palsy who use augmentative and alternative communication (AAC). They co-developed a

Framework that guides researchers in creating accessible methods, materials, and environments for meaningful AAC user involvement in research as research partners and participants. The Framework addresses power imbalance, accessibility, researcher capability, time, recruitment, communication supporters, methods, ethics, and consent. The work was published in the *International Journal of Qualitative Methods*, with a plain English summary video and a practical Toolkit to support application.

Access the toolkit by [clicking here](#)

Access the article by [clicking here](#)

Dissemination has included co-presentations with OGOV members through webinars and at national and international conferences, ensuring wide reach and engagement within research and disability communities



## CP-Achieve and AusACPDM symposia

CP-Achieve hosted three national symposia in partnership with the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), each focused on improving the health, wellbeing, and participation of adolescents and young adults with cerebral palsy. Across the three events, more than 650 people attended, including researchers, clinicians, people with lived experience, policy makers, and advocates.

Topics reflected life areas identified by young people with cerebral palsy such as education, employment, relationships, and community participation. Each symposium featured strong consumer involvement, with individuals with cerebral palsy and their families sharing insights and shaping discussions, ensuring the research remained grounded in lived experience and focused on real-world impact.



## CP-Achieve Webinar Series

The CP-Achieve webinar series was designed to share knowledge, spark connection, and engage people with an interest in improving the lives of young people with cerebral palsy. The sessions highlighted impactful research from CP-Achieve, our collaborators, and leaders in the field, and featured insights from people with lived experience, families, clinicians, and researchers.

The series provided a platform for open discussion, learning, and collaboration, fostering stronger connections between research, practice, and the cerebral palsy community. All webinars were recorded and made freely available to ensure accessibility and ongoing impact.

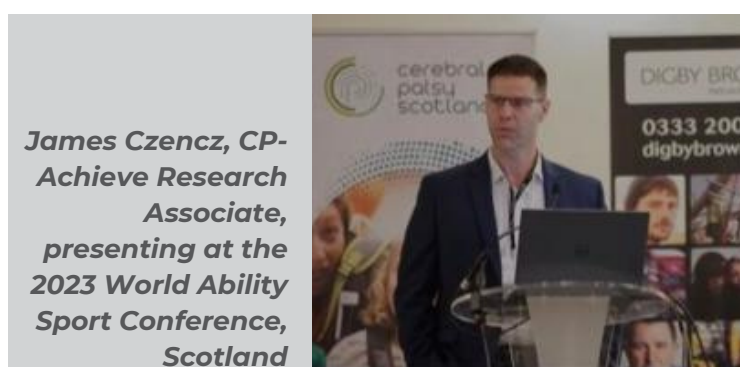
# Awards and Recognition

The research conducted across CP-Achieve received awards and recognition at local, national, and international levels, reflecting both the quality of research outputs and their translation into practice, policy, and community benefit.

Several PhD students and postdoctoral researchers were recipients of these awards, demonstrating how CP-Achieve supported the growth, skill development, and career progression of emerging researchers, while also advancing capacity across the broader health and disability sector.

## Awards

- **Czencz, J.** (2022). Best Presentation – Healthy Brain and Mind Research Centre Conference Day, Australian Catholic University.
- **Czencz, J.** (2023). First Place Presentation, 3MT Competition – ACU: “Unleashing the potential of adults with complex CP through community-based physical activity.”
- **Czencz, J.** (2023). Garry Kesler Award – Best Student Presentation – World Ability Sport Conference, Scotland.
- **Ding, J.** (2022). Best Oral Presentation – 4th Physiotherapy Seminar Series, Monash University.
- **Ding, J.** (2023). Third place- European Academy of Childhood Disability (EACD) Early Career Researcher Award.
- **McKenzie, G.** (2021). Harry Jan Kesler Award for Best Student Presentation – Cerebral Palsy International Sports and Recreation Association Conference: “Finding what works for me” – A qualitative study of gym participation for young adults with cerebral palsy.
- **McKenzie, G.** (2023). St Vincent's Hospital Allied Health Excellence Award – Research and Innovation category.
- **Smith, N.** (2024). Best Oral Paper – Child and Adolescent Health Service (CAHS) Research Symposium, Allied Health.
- **Smith, N.** (2025). MESISIG Prize for Excellence in Methods and Trustworthiness — Methodology, Evidence Synthesis, and Implementation Special Interest Group (International Association for the Study of Pain) – International Symposium on Paediatric Pain, Glasgow, UK.



## Scholarships, Travel Grants, Career Development Awards

- **Carey, J.** (2023). University of Melbourne Melbourne Travel Abroad Scholarship (MATS).
- **Carey, J.** (2024). University of Melbourne Melbourne Travel Abroad Scholarship (MATS).
- **Carey, J.** (2025). Felice Rosemary Lloyd Scholarship – Awarded by the Equity Trustees.
- **Cleary, S. (2023).** Child and Adolescent Health Service (CAHS) Postdoctoral Travel Grant – Attendance at European Academy of Childhood Disability (EACD) Conference, Slovenia – \$3,500.
- **Cleary, S.** (2023) Healthy Trajectories Scholarship – McMaster University Microcertification: Family Engagement in Research.
- **Honan, I.** (2023). Franklin Women’s Scholarship – Awarded to attend European Academy of Childhood Disability (EACD) Conference.
- **Imms, C.** (2021). Kushner Invited Lectureship – University of Toronto, Holland Bloorview, Canada.
- **Imms, C.** (2022). Norrington Lectureship – Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Gold Coast Conference.
- **Imms, C.** (2023). Robert Hill Memorial Developmental Pediatric Medical Education Fund – British Columbia Children’s Hospital, Vancouver, Canada.
- **Pennachia, J.** (2023). Melbourne Abroad Travelling Scholarship – University of Melbourne travel support – \$4,000.
- **Pennachia, J.** (2024). Murdoch Children’s Research Institute Student Conference Support Award – Conference support – \$1,250.
- **Walsh, M.** (2023). Higher Degree

Research Conference Grant – Faculty of Health, Deakin University – \$3,000.

- **Walsh, M.** (2023). School Higher Degree Research Grant – Faculty of Health, Deakin University – \$4,000.

## Research Project Grants Awarded

- **Cleary, S.** 2023 Healthy Trajectories Seed Grant- CP-Pathfinding: Co-design of a lifestyle module to empower young adults with cerebral palsy in health literacy knowledge and participation – \$29,166.
- **Cleary, S.** 2023 Australian Physiotherapy Association Physiotherapy Research Foundation Seed Grant – CP-Pathfinding: Fitness for Life, proof of concept for a co-designed lifestyle module for young adults with cerebral palsy – \$12,000.
- **Czencz, J.** 2024 Warrnambool FitSkills Pilot Project – Gym Membership Grant, Healthy Warrnambool Plan – \$1,749.
- **Dutia, I.** 2023 Medical Research Future Fund (MRFF) Early to Mid-Career Researchers Grant – Running for Health: Community-based adaptive exercise for cardiorespiratory health in young people with moderate to severe cerebral palsy – \$768,886.
- **Dutia, I.** 2023 Medical Research Future Fund (MRFF) Effective Treatments and Therapies Grant – Implementation and scale-up of a consumer co-designed physical activity promotion program for people with moderate-to-profound disabilities – \$590,868.
- **Dutia, I.** 2023 Australian Catholic University Faculty of Health Sciences Early to Mid-Career Academic Research Development Scheme – Implementation and scale-up of a

consumer co-designed physical activity promotion program for people with moderate-to-profound disabilities – \$15,000.

- **Headrick, K.** 2023 Cerebral Palsy Alliance PhD Grant – Mixed methods study of process, authenticity and impact of consumer involvement within CP-Achieve’s research programs – \$52,237.
- **Holmes, C.** 2023 Cerebral Palsy Alliance Emerging Researcher Grant – Motorised Movement Therapy in Non-ambulant Adults with Cerebral Palsy: Pilot study investigating cardiometabolic biomarkers, health and wellbeing outcomes – \$99,528.
- **Holmes, C.** 2023 Research Endowment Fund – St Vincent’s Hospital Melbourne – Motorised Movement Therapy in Non-ambulant Adults with Cerebral Palsy – \$16,931.
- **Mulraney, M.** 2024 Melbourne Disability Institute Seeding Grant – Improving the assessment of anxiety and depression in young people with cerebral palsy: Investigating screening procedures and understanding experiences of seeking help – \$35,000.

- **Pennachia, J.** 2021 Australian Group Supporting Communication Inclusion (AGOSCI) Research Grant – \$1,000.
- **Pennachia, J.** 2023 Speech Pathology Australia New Researcher Grant – Project development – \$17,528.
- **Reddihough, D, Tracy, J, O’Keefe, F, Culnane, E, Morgan, P, Birnie, A, Dorfan, D, Pinto, C, Ponza, B.** 2025 National Centre for Excellence in Intellectual Disability Health Grant – A Health Checklist to Improve the Care of People with Cerebral Palsy and Intellectual Disability – Project development and implementation – \$61,930.
- **Walsh, M.** 2021 Australian Group Supporting Communication Inclusion (AGOSCI) Research Grant – Project to support communication inclusion for people with cerebral palsy – \$1,000.
- **Walsh, M, Wallen, M, Gains, J, Reddihough, D, Sellwood, D, Anderson, K** – 2022 State Trustees Australia Foundation grant “Experts in Their Own Lives: Involving People with Cerebral Palsy and Complex Communication Needs in CP-Achieve Research – A Human Right and a Means for Inclusion” – \$19,951.

*Dr Carlee Holmes, CP-Achieve Postdoctoral Research Fellow, and William Dennis attending the Young Adult Complex Disability Clinic at St Vincent’s Hospital, Melbourne as part of the Motorised Movement Therapy in Non-ambulant Adults with Cerebral Palsy: Pilot study*



# CP-Achieve Outputs

**CP-Achieve has advanced research and practice to improve participation, health, and wellbeing for children and young adults with cerebral palsy.**

Over the course of the program, CP-Achieve has generated a substantial body of scholarly and practical outputs including peer-reviewed publications, presentations, workshops, and webinars spanning national and international platforms.

These outputs demonstrate the program's commitment to evidence-based practice, co-production with individuals and families, and knowledge translation to both clinical and community settings contributing to both scientific advancement and practical improvements in service delivery.

The breadth and impact of these outputs highlight CP-Achieve's role in fostering collaboration between researchers, clinicians, community partners, and people with lived experience, ensuring research is both rigorous and meaningful in real-world contexts.

*Professor Christine Imms, CP-Achieve Chief Investigator, and Rohan Symonds, CP-Achieve Consumer Partner, speaking at the CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia*



## Publications

- 1.** Alanen, A., Kallio, M., Culnane, E., Koivisto, M., Pasanen, M., Salanterä, S., Sawyer, S., & Kosola, S. (2024). Anxiety and care experiences in adolescents with chronic health conditions: An international, longitudinal study across the transfer of care. *BMJ Paediatrics Open*, 8(1), e002836. <https://doi.org/10.1136/bmjpo-2024-002836>
- 2.** Anaby, D., Khetani, M., Piskur, B., van der Holst, M., Bedell, G., Schakel, F., de Kloet, A., Simeonsson, R., & Imms, C. (2022). Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and Rehabilitation*, 44(9), 1746–1757. <https://doi.org/10.1080/09638288.2021.1903102>
- 3.** Bekteshi, S., Karlsson, P., De Reyck, L., Vermeerbergen, K., Konings, M., Hellin, P., Aerts, J. M., Hallez, H., Dan, B., & Monbaliu, E. (2022). Eye movements and stress during eye-tracking gaming performance in children with dyskinetic cerebral palsy. *Developmental Medicine & Child Neurology*, 64(11), 1402–1415. <https://doi.org/10.1111/dmcn.15237>
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- 5.** Bhowon, Y., Prendergast, L., Taylor, N., & Shields, N. (2023). Using geospatial analysis to determine the proximity of community gyms for a population-based cohort of young people with cerebral palsy. *Physiotherapy Canada*. <https://doi.org/10.3138/ptc-2022-0064>
- 6.** Carey, J. J., Spittle, A., Imms, C., Shields, N., Wallen, M., O'Keefe, F., Yates, M. J., Skilbeck, H., & Toovey, R. (2025). Adapting experience-based co-design to disability research: Co-producing the CycLink co-design study. *Health Expectations*, 28(3), e70276. <https://doi.org/10.1111/hex.70276>
- 7.** Carey, J. J., Toovey, R., Spittle, A. J., Imms, C., & Shields, N. (2023). Exploring adaptive cycling interventions for young people with disability: An online survey of providers in Australia. *Journal of Clinical Medicine*, 12(17), Article 5523. <https://doi.org/10.3390/jcm12175523>
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- 9.** Cavens, C., Imms, C., Drake, G., Garrity, N., & Wallen, M. (2022). Perspectives of children and adolescents with cerebral palsy about involvement as research partners: A qualitative study. *Disability and Rehabilitation*, 44(16), 4293–4302. <https://doi.org/10.1080/09638288.2021.1900927>
- 10.** Cleary, S. L., Morgan, P. E., Wallen, M., Honan, I., Shields, N., Munzel, F. E., Plummer, J. R., Assaad, C., Karlsson, P., Culnane, E., Ding, J. Y., Holmes, C., Dutia, I. M., Reddihough, D. S., & Imms, C. (2024). Experiences of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. *Developmental Medicine & Child Neurology*, 67(5), 572–590. <https://doi.org/10.1111/dmcn.16196>
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- 12.** Cleary, S., Lami, F., & Wong, B., & Hickey, L. (2023). REsearch with lived experience experts: A planning, onboarding and participation guide for researchers (The RELEE-POP guide). <https://healthy-trajectories.com.au/resources/relee-pop-research-with-lived-experience-experts-a-planning-onboarding-and-participation-guide-for-researchers/>
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- 14.** Culnane, E., Efron, D., Williams, K., Marraffa, C., Antolovich, G., Prakash, C., & Loftus, H. (2023). Carer perspectives of a transition to adult care model for adolescents with an intellectual disability and/or autism spectrum disorder with mental health comorbidities. *Child: Care, Health and Development*, 49(2), 281–291. <https://doi.org/10.1111/cch.13040>
- 15.** Culnane, E., Loftus, H., Efron, D., Williams, K., Di Iorio, N., Shepherd, R., Marraffa, C., Lubitz, L., Antolovich, G., & Prakash, C. (2020). Development of the Fearless, Tearless Transition model of care for adolescents with an intellectual disability and/or autism spectrum disorder with mental health comorbidities. *Developmental Medicine & Child Neurology*, 63(5), 560–565. <https://doi.org/10.1111/dmcn.14766>
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- 19.** Ding, D., Eres, R., & Surkalim, D. L. (2022). A lonely planet: Time to tackle loneliness as a public health issue. *BMJ (Clinical Research Ed.)*, 377, o1464. <https://doi.org/10.1136/bmj.o1464>
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- 31.** Graham, K., Rutz, E., Thomason, P., & Willoughby, K. (2023). Reducing spasticity does not prevent hip displacement in cerebral palsy. *Developmental Medicine & Child Neurology*, 65(8), 1123. <https://doi.org/10.1111/dmcn.15613>
- 32.** Granlund, M., & Imms, C. (2024). Participation as a means—implications for intervention reasoning. *Frontiers in Rehabilitation Sciences*, 5, 1399818. <https://doi.org/10.3389/fresc.2024.1399818>
- 33.** Granlund, M., Imms, C., King, G., Andersson, A. K., Augustine, L., Brooks, R., Danielsson, H., Gothlander, J., Ivarsson, M., Lundqvist, L. O., Lyngnegård, F., & Almqvist, L. (2021). Definitions and operationalization of mental health problems, wellbeing and participation constructs in children with neurodevelopmental disorders: Distinctions and clarifications. *International Journal of Environmental Research and Public Health*, 18(4), 1656. <https://doi.org/10.3390/ijerph18041656>
- 34.** Harvey, A. R., McKinnon, C. T., Smith, N., Ostojic, K., Paget, S. P., Smith, S., Shepherd, D. A., Lewis, J., & Morrow, A. (2021). 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>
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## Presentations

**1.** Anaby, D., Imms, C., Dada, S., Piskur, B., & Schakel, F. (2022, March 1–5). Let’s LEAP together: Towards a participation-focused practice and a pediatric rehabilitation paradigm shift. *Australasian Academy of Cerebral Palsy and Developmental Medicine / International Alliance of Academies of Childhood Disability (AusACPDM/IAACD) 2022: Better Together (Virtual)*.

**2.** Anaby, D., Imms, C., Piskur, B., van der Holst, M., & Schakel, F. (2022, May). Networking to mobilize new knowledge around participation into practice: The Participation-focused Knowledge Translation (P-KT) roadmap. *34th European Academy of Childhood Disability, Barcelona, Spain*.

**3.** Anaby, D., Vanska, N., Jeglinsky-Kankainen, I., Waisman Nitzan, M., Piskur, B., Goertzen, L., Feron, J., & Imms, C. (2024, May). Orchestrating participation-focused approaches: Partnering with decision makers. *36th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Bruges, Belgium*

**4.** Bannon, N., Wallen, M., Imms, C., Anaby, D., Fredrickson, E., Cassidy, A., DiMarco, A., Hunter, O., Garrity, N., & Cowan, H. (2024, July). Implementation feasibility study: A stakeholder adaptation of Pathways and Resources for Engagement and Participation (PREP) with young adults with complex disability in Australia. *12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia*

**5.** Butchart, J., Yang, Y., Imms, C., & Disney, G. (2025, June). What drives reporting neurodevelopmental disabilities as the underlying cause of death: Certification or statistical coding practices? *37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany*.

**6.** Carey, J. J. (2021, June 17). Going through the gears – My PhD in 3. *Collaborate, Innovate, Achieve: CP-Achieve & AusACPDM Symposium, Murdoch Children’s Research Institute, Melbourne, Australia (Virtual)*.

**7.** Carey, J. J. (2022, March 3). Pathways to research – A PhD student’s journey [Ask

me anything session]. *Better Together: 11th Meeting of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) and 3rd Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD), Melbourne, Australia (Virtual)*.

**8.** Carey, J. J. (2022, October). Five things I wish I’d known about co-design: Reflections of a graduate researcher. *Methods and Implementation Support for Clinical and Health Research Hub (MISCH), University of Melbourne*

**9.** Carey, J. J. (2023, August 3–4). Cycling is for everyone: Adaptive cycling for young people with cerebral palsy functioning at GMFCS Level IV and V. *CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia*.

**10.** Carey, J. J. (2023, August 3–4). Picture this: Photo-methods in co-design. *PhD Bright Lights Presentation, CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia*.

**11.** Carey, J. J. (2023, August 4). Fitness for life: Cycling for everyone – Adaptive cycling for young people with cerebral palsy functioning at GMFCS Level IV and V [Ask me anything session]. *CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia*.

**12.** Carey, J. J. (2023, February). Bike-riding for all abilities. *Australian Physiotherapy Association Online Lecture Series: Exercise, Sport and Participation in the National Disability Insurance Scheme (NDIS) Context [Virtual]*.

**13.** Carey, J. J. (2024, July 10). Using co-design to develop the CycLink program principles [Webinar]. *CP-Achieve [Virtual]*. <https://www.youtube.com/watch?v=8MUZbpiZQvs>

**14.** Carey, J. J. (2024, June 6). Partnering to pedal with disability: Insights from Australia [Webinar]. *CP-Life Webinar, Royal College of Surgeons Ireland, Dublin, Ireland*. <https://cpresearchireland.eu/webinars/>

**15.** Carey, J. J., Spittle, A. J., Toovey, R., Wallen, M., Shields, N., Yates, M., O’Keefe, F., & Imms, C. (2025, June). Evaluating the involvement of consumers and community partners during online co-design of a community cycling program (CycLink). *37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany*.

**16.** Carey, J. J., Toovey, R., O’Keefe, F., Yates, M., & Skilbeck, H. (2023, June 26). *CycLink Co-Design Study. Melbourne Disability Institute, University of Melbourne, Community of Practice Series, Melbourne, Australia*.

**17.** Carey, J. J., Toovey, R., Spittle, A. J., Imms, C., & Shields, N. (2023, October 5–7). Delivering adapted cycling interventions for young people with disability in Australia — Who’s doing

- what? IGNITE 2023: Australian Physiotherapy Association Conference, Brisbane, Australia
- 18.** Carey, J. J., Toovey, R., Spittle, A. J., Imms, C., & Shields, N. (2023, October 5–7). Exploring barriers and facilitators to participation in outdoor adapted cycling for young people with disability: Providers' perspectives. IGNITE 2023: Australian Physiotherapy Association Conference, Brisbane, Australia.
- 19.** Carey, J. J., Toovey, R., Spittle, A. J., Imms, C., & Shields, N. (2024, May 29–June 1). Researching co-design together: Developing an experience-based co-design study protocol [Poster]. 36th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Bruges, Belgium.
- 20.** Carey, J. J., Toovey, R., Spittle, A. J., Imms, C., & Shields, N. (2024, May 29–June 1). Using co-design as a route towards cycling participation: Development of intervention principles. 36th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Bruges, Belgium.
- 21.** Carroll, J., Imms, C., Rameckers, E., Mano da Costa, T., & Mayston, M. (2024, May). An exploration of clinical decision making across different therapy approaches for children living with cerebral palsy. 36th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Bruges, Belgium.
- 22.** Cleary, S. (2022, March 1–5). A systematic review and meta-analysis of the effects of community-based physical activity programs for adolescents and young adults with disability. Better Together: 11th Meeting of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) and 3rd Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD), Melbourne, Australia (Virtual).
- 23.** Cleary, S. (2023). Research Works Podcast, European Academy of Childhood Disability (EACD) Edition, Day 2.
- 24.** Cleary, S., et al., & Imms, C. (2024, July). The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 25.** Cleary, S., Imms, C., Morgan, P., Plummer, J., & Pope, A. (2024, May 22). Doing the important things of life – Understanding the participation of young adults with cerebral palsy [Webinar]. My CP Guide. [https://www.youtube.com/watch?v=qbE8xE\\_dE9o](https://www.youtube.com/watch?v=qbE8xE_dE9o)
- 26.** Cleary, S., Morgan, P., et al. (2023, May 19). The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. International Cerebral Palsy Symposium, Belfast, Northern Ireland.
- 27.** Cleary, S., Morgan, P., et al. (2023, May 24–27). The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. 35th Annual Meeting of the European Academy of Childhood Disability (EACD), Ljubljana, Slovenia
- 28.** Cleary, S., Willis, C., & Shields, N. (2023, May 24–27). The effects of community-based physical activity interventions on adolescents and young adults with disability: A systematic review. 35th Annual Meeting of the European Academy of Childhood Disability (EACD), Ljubljana, Slovenia
- 29.** Cleary, S., Willis, C., & Shields, N. (2023, May). The effects of community-based physical activity interventions on adolescents and young adults with disability: A systematic review. Department of Rehabilitation, Erasmus University Medical Centre, Rotterdam, The Netherlands.
- 30.** Cleary, S., Willis, C., & Shields, N. (2023, October 5–7). Supporting participation in physical activity for adolescents and young adults with cerebral palsy: Provider perspectives. IGNITE 2023: Australian Physiotherapy Association Conference, Brisbane, Australia.
- 31.** Coghill, D. (2023, August 3). Cerebral palsy and mental health [Keynote address]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 32.** Culnane, E. (2023, September 10–13). "From pond to sea" – Are we doing enough to ensure the best lifelong outcomes for our patients? Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ) 6th Annual Scientific Meeting, Hobart, Australia.
- 33.** Culnane, E. (2024, August). 'Boundaries in transition care'. Schwartz Grand Round, The Royal Children's Hospital, Melbourne, Australia.
- 34.** Culnane, E. (2024, November 12). Transition Compass: What do AYAs and healthcare professionals want in a transition intervention. Youth Health Conference, Brisbane, Australia.
- 35.** Czencz, J. (2021, December 10). The effect of exercise interventions on participation and quality of life for adults with cerebral palsy: Systematic review. Cerebral Palsy International Sport & Recreation Association (CPISTRA) International Conference (Virtual).
- 36.** Czencz, J. (2021, June 18). PhD in 3 – 3 Minute Thesis presentation. Collaborate, Innovate, Achieve: CP-Achieve & AusACPDM Symposium, Murdoch Children's Research Institute, Melbourne, Australia (Virtual).
- 37.** Czencz, J. (2023). PhD project plan. Australian Catholic University (ACU) Healthy Brain and Mind Research Centre Research Forum.
- 38.** Czencz, J. (2023, July). Unleashing the potential of adults with complex cerebral palsy through community-based physical activity. Three Minute Thesis (3MT), Australian Catholic University, Melbourne, Australia.
- 39.** Czencz, J. (2023, October 20–21). Exploring the needs and wants of adults with cerebral palsy who use wheelchairs to participate in physical activity: A qualitative study. World Ability Sport Conference, Edinburgh, Scotland.
- 40.** Czencz, J. (2023, October 3). Let's get active – Exploring the needs and wants of adults with cerebral palsy who use wheelchairs to participate in physical activity [Consumer session]. CP Scotland, Glasgow, Scotland.
- 41.** Czencz, J. (2023, October). Research update: Promoting exercise for adults with cerebral palsy. Central Remedial Clinic, Dublin, Ireland.
- 42.** Czencz, J. (2025, August 17–19). Feasibility of FitSkills for an adult with cerebral palsy using a wheelchair in a regional setting: A mixed-methods case study. HEPA Europe – European Network for the Promotion of Health-Enhancing Physical Activity, Kaunas, Lithuania.
- 43.** Czencz, J., Shields, N., Wallen, M., Wilson, P. H., McGuckian, T. B., & Imms, C. (2022, March 5). The effect of exercise interventions on participation and quality of life for adults with cerebral palsy: Systematic review. Australasian Academy of Cerebral Palsy and Developmental Medicine Conference (Virtual).
- 44.** Czencz, J., Wallen, M., Shields, N., Imms, C., & Wilson, P. H. (2024, August 19–21). Understanding the wants and needs of adults with cerebral palsy who use wheelchairs to participate in community-based physical activity: A qualitative study. HEPA Europe – European Network for the Promotion of Health-Enhancing Physical Activity, Dublin, Ireland.
- 45.** Ding, J. (2024, July 31). CP-Pathfinding: Your health. Infinite Horizons Workshop: Babies to Adults with Cerebral Palsy, 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, QLD, Australia.
- 46.** Ding, J. (2025, April 3). Branching into adulthood: Views of young adults with cerebral palsy on navigating life, their information-seeking behaviours and how to support their healthcare decision-making. CP-Achieve & AusACPDM Cerebral Palsy Symposium 2025: Progress and Possibilities, Melbourne, VIC, Australia.
- 47.** Ding, J., & Cleary, S. (2026, March 3). Partnership in practice: Co-designing CP-specific health and fitness resources for young adulthood [Pre-conference workshop presentation]. 13th AusACPDM Biennial Conference "Transforming Care Across Oceans," Hobart, TAS, Australia.
- 48.** Ding, J., Cleary, S., & Morgan, P. (2022, May 31). Exploring young adulthood: Experiences and perceptions of those

- with cerebral palsy. 4th Physiotherapy Seminar Series, Monash University, Melbourne, VIC, Australia.
- 49.** Ding, J., Cleary, S., & Morgan, P. (2023, August 31). Enhancing the participation in daily life of adolescents and young adults with cerebral palsy: Thesis overview. Work in Progress Seminar, Murdoch Children's Research Institute, Melbourne, VIC, Australia.
- 50.** Ding, J., Cleary, S., & Morgan, P. (2023, August 3–4). "Branching out into adulthood": A qualitative study exploring the experiences and perceptions of participation for young people with cerebral palsy. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 51.** Ding, J., Cleary, S., & Morgan, P. (2023, May 24–27). Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy. 35th Annual Meeting of the European Academy of Childhood Disability (EACD), Ljubljana, Slovenia.
- 52.** Ding, J., Cleary, S., & Morgan, P. (2023, May 25). A mixed-methods systematic review of health literacy in adolescents and young adults with cerebral palsy, and the relationship to quality of life. 35th Annual Meeting of the European Academy of Childhood Disability (EACD), Ljubljana, Slovenia.
- 53.** Ding, J., Cleary, S., & Morgan, P. (2023, May 30). Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy. Rehabilitation Department, Erasmus University Medical Centre, Rotterdam, The Netherlands
- 54.** Ding, J., Cleary, S., & Morgan, P. (2023, October 24). A mixed-methods systematic review of health literacy in adolescents and young adults with cerebral palsy, and the relationship to quality of life. Murdoch Children's Research Institute Symposium, Melbourne, VIC, Australia
- 55.** Ding, J., Cleary, S., & Morgan, P. (2024, August 1). Characteristics of NDIS capacity building goals in young people with cerebral palsy: A cross-sectional analysis of publicly available data [Poster]. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, QLD, Australia.
- 56.** Ding, J., Cleary, S., & Morgan, P. (2024, February 21). Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy. 36th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) Awards Celebration Event (Virtual).
- 57.** Ding, J., Cleary, S., & Morgan, P. (2024, May 22). Exploring young adulthood: Experiences of those with cerebral palsy [Webinar presentation]. CP-Achieve Webinar Series.
- 58.** Dutia, I. M. (2021, December 2). Conducting accessible research for people with complex needs. Australian Catholic University School of Allied Health Research Network, Brisbane, Australia.
- 59.** Dutia, I. M., Eres, R., Sawyer, S. M., Johnston, L., Reddihough, D., Cleary, S., & Coghill, D. (2023, October 11). Fatigue experienced by people with cerebral palsy: A systematic review of assessment tools and decision tree. Australian Physiotherapy Association Conference, Brisbane, QLD, Australia.
- 60.** Frederico Vallim, F., Graham, K., Guimarães, J. A. M., & Nogueira-Barbosa, M. H. (2024, October 23–26). Medialization at the osteotomy site may reduce relapse after varus de-rotational osteotomy (VDRO) of the proximal femur in cerebral palsy. 78th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AAPDM), Quebec City, Canada.
- 61.** Giles, S. (2022, September 16). Royal Children's Hospital Education Hub Podcast "Teach, Think, Treat" episode "Research for beginners" [Online].
- 62.** Giles, S. (2023, August 3–4). Cerebral palsy and mental health: Where are we now and initiatives to improve wellbeing. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia
- 63.** Giles, S. (2023, August 3–4). Parents and wellbeing. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 64.** Giles, S., Holmes, C., Imms, I., Coghill, D., Tracy, J., Dutia, I., Mulraney, M., Eres, R., & Reddihough, D. (2024, August 1–3). Understanding health profiles and clinical characteristics of a cohort of young Australians with cerebral palsy [Poster]. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 65.** Giles, S., Imms, I., Shields, N., Holmes, C., Coghill, D., & Reddihough, D. (2024, August 1–3). Exploring the mental health and wellbeing of young people with cerebral palsy. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 66.** Graham, K., Davids, J. R., Thomason, P., & Rutz, E. (2024, October). MINISYMP08: Knee surveillance in children with diplegia. 78th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AAPDM), Quebec City, Canada.
- 67.** Graham, K., Rutz, E., Holmes, C., & Thomason, P. (2023, August 3–4). Musculoskeletal issues: What we don't talk about. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 68.** Harvey, A. (2021, June 17–18). Expert panel discussion on pain and fatigue. Collaborate, Innovate, Achieve: CP-Achieve & AusACPDM Symposium, Murdoch Children's Research Institute, Melbourne, Australia (Virtual).
- 69.** Harvey, A. (2023, October 1–4). Pain in children and young people with cerebral palsy: Challenges and solutions. International Symposium on Pediatric Pain (ISPP), Halifax, Nova Scotia, Canada.
- 69.** Harvey, A., McKinnon, C., Smith, N., Ostojic, K., Paget, S., Smith, S., Shepherd, D., Lewis, J., & Morrow, A. (2022). Establishing consensus for the assessment of chronic pain in children and young people with cerebral palsy: A Delphi study. Australasian Academy of Cerebral Palsy and Developmental Medicine / International Alliance of Academies of Childhood Disability (AusACPDM/IAACD) 2022: Better Together (Virtual).
- 70.** Harvey, A., Smith, N., Smith, M., Doyle, C., & Hogan, A. (2023, August 3–4). Chronic pain assessment for children and young people with cerebral palsy. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 71.** Harvey, A., Smith, N., Smith, M., Doyle, C., & Hogan, A. (2023, October 1–4). Co-designing pain assessment for children and young people with cerebral palsy. International Symposium on Pediatric Pain (ISPP), Halifax, Nova Scotia, Canada.
- 72.** Henry, G. (2025, June). Experiences of a mindfulness telehealth program for adults with cerebral palsy. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 73.** Hickey, L. (2023, March 29). Transition to independent living. CP-Achieve Webinar Series.
- 74.** Hickey, L., Harms, L., Reddihough, D., Imms, C., Culnane, E., & Saunders, V. (2024, July 31–August 3). Families' perspectives on transitioning young adults with cerebral palsy to independent living. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 75.** Hickey, L., Harms, L., Reddihough, D., Imms, C., Culnane, E., & Saunders, V. (2024, July 31–August 3). Families' perspectives on transitioning young adults with cerebral palsy to independent living. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 76.** Hickey, L., Harms, L., Reddihough, D., Imms, C., Culnane, E., & Saunders, V. (2024, May). Families' perspectives on transitioning young adults with cerebral palsy to independent living. Universitas 21 Community of Practice Inaugural Conference.

- 77.** Hickey, L., Hunter, O., Hooke, P., Tracy, J., & Culnane, E. (2023, August 3–4). Independent living: “My mum doesn’t know what colour my undies are!” CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 78.** Hickey, L., Silcock, N., Haveri, A., Haveri, K., & Holmes, C. (2025, April 3–4). Conversations about independent living: Exploring experiences of young people with cerebral palsy and their families. CP-Achieve & AusACPDM Cerebral Palsy Symposium 2025: Progress and Possibilities, Melbourne, VIC, Australia.
- 79.** Holmes, C. (2023, November 21–23). Transforming the health and wellbeing of people with complex disabilities through motorised cycling. Oceania Seating Symposium, Melbourne, VIC, Australia.
- 80.** Holmes, C. (2023, October 20–21). Transforming the health and wellbeing of people with complex disabilities through motorised cycling. World Ability Sport Conference, Edinburgh, Scotland (Hybrid event).
- 81.** Holmes, C. (2024, April 24). CP-Achieve participant characteristics survey: Physical, mental, and sexual health. CP-Achieve Webinar Series [Online].
- 82.** Holmes, C. (2025, April 17). Physical activity options for young adults with more complex forms of cerebral palsy. CP-Achieve & AusACPDM Cerebral Palsy Symposium 2025: Progress and Possibilities – Celebrating 5 Years of Research Through Lived Experience and Planning the Future, Melbourne, Australia.
- 83.** Holmes, C. (2025, June 10). Postural asymmetry in non-ambulant adults with cerebral palsy: Measurement and clinical application of the Goldsmith Indices of Body Symmetry. 4th Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD) & 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 84.** Holmes, C. (2025, June 11). Home-based motorised cycling in non-ambulant adults with cerebral palsy: A feasibility study. 4th Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD) & 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 85.** Holmes, C. (2025, October 4). A clinical approach to the measurement of postural asymmetry in adults with cerebral palsy. Australian Physiotherapy Association Scientific Conference 2025, Adelaide, Australia.
- 86.** Holmes, C., & Giles, S. (2024, August 1). Understanding health profiles and clinical characteristics of a cohort of young Australians with cerebral palsy. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 87.** Holmes, C., & Giles, S. (2025, April 17). The Understanding Survey: What does it tell us and how can we use the findings? CP-Achieve & AusACPDM Cerebral Palsy Symposium 2025: Progress and Possibilities – Celebrating 5 Years of Research Through Lived Experience and Planning the Future, Melbourne, Australia.
- 88.** Holmes, C., & Rowe, A. (2023, November 21–23). What is happening under the covers? Bed positioning assessment and goal setting. Oceania Seating Symposium, Melbourne, VIC, Australia.
- 89.** Holmes, C., & Rowe, A. (2024, July 12). Bed positioning assessment and goal setting. One-day Workshop, Melbourne, Australia.
- 90.** Holmes, C., Fredrickson, E., Saunders, V., & Murphy, D. (2023, August 3–4). Pathways between education and employment. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 91.** Holmes, C., Morgan, P., & McKenzie, G. (2025, October 3). Cerebral palsy: A lifespan approach to health and wellbeing. Australian Physiotherapy Association Scientific Conference 2025, Adelaide, Australia.
- 92.** Holmes, C., Shields, N., Morgan, P., Brock, K., McKenzie, G., & Reddihough, D. (2024, August 5–9). Home-based motorised cycling in non-ambulant adults with cerebral palsy: A feasibility study [E-poster]. St Vincent’s Hospital Melbourne Research Week, Melbourne, Australia.
- 93.** Honan, I., Stephenson, C., & Karlsson, P. (2022). Neuropsychological Assessment for Children with Cerebral Palsy and Severe Motor Impairment CogTEST-C. Paper presented at the APS College of Clinical Neuropsychologists Conference, 4–5 November 2022, Sydney, Australia.
- 94.** Howard, J., Shore, B.J., Graham, K., & Rutz, E. (2024, October 23–26). MINISYMP20: Surveillance and management of hip displacement in children with cerebral palsy: Clinical and ethical dilemmas. 78th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPD), Quebec City, Canada.
- 95.** Imms, C. (2021, August). Strategies for successful participation: Lessons from adults with cerebral palsy. 4th Asia-Ocean Congress of Neuro-Rehabilitation (AOCNR 2021) (Virtual).
- 96.** Imms, C. (2021, December). Strategies for successful participation: Lessons from adults with cerebral palsy [Keynote]. 4th International Developmental Pediatrics Association Congress & Arab Network for Early Childhood Development (Virtual).
- 97.** Imms, C. (2021, June). Participation-focused therapy: Starting with the end in mind [Keynote]. 6th Pediatric Rehabilitasyon Kongresi (Virtual).
- 98.** Imms, C. (2021, November). Participating in moving knowledge to action: Think ethically, behave intentionally and try [Keynote]. Kids Brain Health Network Conference (Virtual).
- 99.** Imms, C. (2022, February). Invited keynote: Promoting participation in children with disabilities: It’s everyone’s business. Kushnir Lectureship; Bloorview.
- 100.** Imms, C. (2022, June). Norrington Lecture (Award): Child onset disability: Taking a life course perspective to enable successful transitions and optimal participation. Rehabilitation Medicine Society of Australia and New Zealand Conference, Gold Coast, Australia.
- 101.** Imms, C. (2022, October). Invited keynote: CP Achieve: Attending and being involved in research about participation. 9th Annual CP-NET Science and Family Day.
- 102.** Imms, C. (2022, September). Invited keynote: An overview of evidence from the CAPA Special Edition. Capture the Magic: Participation for All Conference, Beitostolen, Norway.
- 103.** Imms, C. (2022, September). Invited speaker: Participation: Starting with the end in mind. European Academy of Childhood Disability: Early Career Researcher Forum.
- 104.** Imms, C. (2023, July 29–30). Participation for everyone: Reaching ultimate outcomes. 6th National Conference of the Australian ADHD Professionals, Melbourne, Australia.
- 105.** Imms, C. (2023, June). Providing participation-focused rehabilitation for those with child-onset disability. Chinese Association of Rehabilitation Medicine – Paediatric Rehabilitation Conference, Chengdu, China.
- 106.** Imms, C. (2023, September). Awarded lectureship: Participation in research as a right and a valued life situation for young people with disability. Robert Hill Memorial Lectureship, British Columbia Children’s Hospital, Vancouver, Canada.
- 107.** Imms, C. (2023, September). How the macro environment shapes the research agenda. Robert Hill Memorial Lectureship, British Columbia Children’s Hospital, Vancouver, Canada.
- 108.** Imms, C. (2023, September). Strategies and pitfalls when involving children and families in research. Robert Hill Memorial Lectureship, British Columbia Children’s Hospital, Vancouver, Canada.
- 109.** Imms, C. (2024, November). Invited keynote: The family of participation related constructs. Participation – Inclusion in Action Conference, Singapore.
- 110.** Imms, C. (2025, February). Invited presentation: Components of effective participatory models for child growth and development interventions with an India-specific focus. Christian Medical College, Vellore, India.
- 111.** Imms, C. (2025, June). Accessible and accommodating health services: Australian approaches. 37th Annual

- Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 112.** Imms, C. (2023, September). How the macro environment shapes the research agenda. Robert Hill Memorial Lectureship, British Columbia Children's Hospital, Vancouver, Canada.
- 113.** Imms, C. (2023, September). Strategies and pitfalls when involving children and families in research. Robert Hill Memorial Lectureship, British Columbia Children's Hospital, Vancouver, Canada.
- 114.** Imms, C. (2024, November). Invited keynote: The family of participation related constructs. Participation – Inclusion in Action Conference, Singapore.
- 115.** Imms, C. (2025, June). Accessible and accommodating health services: Australian approaches. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 116.** Karlsson, P. (2022, May). Research updates – Technologies. In Therapy Conference, Sydney, Australia.
- 117.** Karlsson, P. (2022, November). Technology across the lifespan with a focus on mobility, communication and cognition. In Neurology Update Seminar, Sydney, Australia.
- 118.** Karlsson, P. (2022, October). Emerging Assistive Technology for Communication. In APAC IAP, Association in Favor of People with Cerebral Palsy. First International Forum on Cerebral Palsy, Mexico City, Mexico.
- 119.** Karlsson, P., & McEwan, A. (2021, July). Emerging technologies for communication. Speech Pathology Discipline Research Symposium, Sydney, Australia.
- 120.** Karlsson, P., Arthur, N., & Davies, N. (2022, 3–6 September). Eyes on Communication Research Group and Advisory Panel: New Clinical Guidelines 2021 - Eye-gaze control technology for children and adults with cerebral palsy. Paper presented at the 15th Biennial AGOSCI Conference, Tasmania, Australia.
- 121.** Karlsson, P., Denver Deramore, B., & Wallen, M. (2021, June 18–19). Eyes on Communication Research Group and Advisory Panel: New clinical guidelines 2021 – Eye-gaze control technology for children and adults with cerebral palsy. Australasian Academy of Cerebral Palsy & Developmental Medicine and International Alliance of Academies of Childhood Disability "Better Together" Conference (Virtual).
- 122.** Karlsson, P., Griffiths, T., Himmelmann, K., Clarke, M., Allsop, A., Monbaliu, E., Bekteshi, S., Pereksles, R., & Wallen, M. (2021, September 13–17). Clinical guidelines for eye-gaze control for people with cerebral palsy. Communication Matters Conference (Virtual).
- 123.** Kilgour, G., & Imms, C. (2022, September). Aligning theory and practice: Using the Family of Participation-Related Constructs to guide intervention planning and fidelity. American Academy for Cerebral Palsy and Developmental Medicine, Las Vegas, USA.
- 124.** Kilgour, G., & Imms, C. (2022, September). Involvement: Moving beyond enjoyment when considering participation experiences. American Academy for Cerebral Palsy and Developmental Medicine, Las Vegas, USA.
- 125.** Kilgour, G., Stott, N., Adair, B., Steele, M., Hogan, A., & Imms, C. (2025, June). Exploring the implementation of a participation-focused intervention on the constructs described within the Family of Participation-Related Constructs: A qualitative follow-up study. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 126.** Kilgour, G., Stott, S., Steele, M., Adair, B., Hogan, A., & Imms, C. (2023, June). Effects of a high-level mobility programme on sustained participation of adolescents with cerebral palsy: A single subject research design study. International Society of Adapted Physical Activity Conference, Dunedin, New Zealand.
- 127.** Kilgour, G., Stott, S., Steele, M., Adair, B., Hogan, A., & Imms, C. (2023, June). More than having fun: Understanding the experience of involvement in physical activity. International Society of Adapted Physical Activity Conference, Dunedin, New Zealand.
- 128.** Kilgour, G., Stott, S., Steele, M., Adair, B., Hogan, A., & Imms, C. (2023, June). Navigating their own waka: The journey to sustain participation in physical activity with cerebral palsy and their parents. International Society of Adapted Physical Activity Conference, Dunedin, New Zealand.
- 129.** Kilgour, G., Stott, S., Steele, M., Adair, B., Hogan, A., & Imms, C. (2023, March). Experiencing the journey to sustained participation in physical activity: Navigating your own waka (Māori canoe). Kids Rehab Conference, Brisbane, Australia.
- 130.** Knudsen, D., Dimarco, A., Imms, C., Garrity, N., Hunter, O., & Wallen, M. (2024, July 31–August 3). Consumer involvement in research: A mixed-methods evaluation of the involvement of young adults with disability in an intervention feasibility study. *Developmental Medicine & Child Neurology*, 66(S66), 70. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia
- 131.** Knudsen, D., Dimarco, A., Imms, C., Garrity, N., Hunter, O., & Wallen, M. (2025, June). CEval conference abstract – EACD combined International Alliance of Academies of Childhood Disability. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 132.** Knudsen, D., Wallen, M., Dimarco, A., & Imms, C. (2024, July). Evaluating consumer involvement in research. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 133.** Manning, P., Shaw, B., Ponza, B., Wong, S., & Walsh, M. (2023, September 20). Hearing our voices: Perspectives from CP-Achieve's advisory group of AAC users [Webinar]. CP-Achieve Webinar Series.
- 134.** McKenzie, G. (2021, December 8–11). "Finding what works for me" – A qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Cerebral Palsy International Sport & Recreation Association (CPISRA) International Conference (Virtual).
- 135.** McKenzie, G. (2021, December 8–11). Barriers and facilitators of physical activity participation for young people and adults with childhood-onset physical disability: A mixed-methods systematic review. Cerebral Palsy International Sport & Recreation Association (CPISRA) International Conference (Virtual).
- 136.** McKenzie, G. (2021, March 10). What are the barriers and facilitators to participating in community gym exercise for young adults with cerebral palsy? A qualitative study. Living with Disability Research Centre, La Trobe University (Virtual).
- 137.** McKenzie, G. (2021, March 11–14). Barriers and facilitators of physical activity participation for young people and adults with childhood-onset physical disability: A mixed-methods systematic review. Australasian Academy of Cerebral Palsy & Developmental Medicine Annual Meeting, Perth, Australia
- 138.** McKenzie, G. (2022, August 31). 'Finding what works for me' – Supporting gym participation for young adults with cerebral palsy [Webinar]. CP-Achieve Webinar Series.
- 139.** McKenzie, G. (2022, March 1–5). 'Finding what works for me' – A qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Australasian Academy of Cerebral Palsy and Developmental Medicine / International Alliance of Academies of Childhood Disability (AusACPDM/IAACD) 2022: Better Together (Virtual).
- 140.** McKenzie, G. (2022, October 10). Disability and physical activity. Australian Physiotherapy Association Conference, Melbourne, Australia.
- 141.** McKenzie, G. (2023, April 29). 'Finding what works for me' – A qualitative study of factors influencing community gym participation for young adults with cerebral palsy. The Research Works Podcast, Season 3, Episode 6. <https://www.youtube.com/watch?v=DQoMOXSrUKc>
- 142.** McKenzie, G. (2023, August 17–19). 'Finding what works for me' – A qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Women in

- Sport Conference, Melbourne, Australia.
- 143.** McKenzie, G. (2023, August 3–4). \*‘PhD in 3’. \* CP-Achieve and AusACPD 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 144.** McKenzie, G. (2023, August 3–4). Creating inclusive gym environments. CP-Achieve and AusACPD 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 145.** McKenzie, G. (2023, February 9). Health clubs and cerebral palsy. Aquatic and Recreation Victoria Diversity and Inclusion Forum, Melbourne, Australia.
- 147.** McKenzie, G. (2023, February 9). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. Aquatics and Recreation Victoria Diversity and Inclusion Forum, Victoria, Australia.
- 146.** McKenzie, G. (2023, May 24–27). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. 35th Annual Meeting of the European Academy of Childhood Disability (EACD), Ljubljana, Slovenia.
- 147.** McKenzie, G. (2023, November 30). ‘More confident within myself’ – Social strategies supporting young adults with disability in community gyms, a GYM-SPARC project [Webinar]. Disability Sport and Recreation Victoria, International Day of People with Disability (Virtual).
- 148.** McKenzie, G. (2025, June 25–28). A co-production approach to developing resources to support community physical activity for young adults with cerebral palsy who use wheelchairs. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 149.** McKenzie, G. (2025, June 25–28). Home-based motorised cycling in non-ambulant adults with cerebral palsy: A feasibility study. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Heidelberg, Germany.
- 150.** McKenzie, G., Kennedy, R., Willis, C., & Shields, N. (2023, October 20–21). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. World Ability Sport Conference (Virtual).
- 151.** McKenzie, G., Willis, C., & Shields, N. (2022, August 17–19). ‘Finding what works for me’ – A qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Women in Sport Congress, Melbourne, Australia.
- 152.** McKenzie, G., Willis, C., Kennedy, R., & Shields, N. (2023, May 19). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. International Cerebral Palsy Symposium, Belfast, Northern Ireland.
- 153.** McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023, May 24–27). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: An e-Delphi study. 35th European Academy of Childhood Disability Annual Meeting, Ljubljana, Slovenia.
- 154.** McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023, May 30). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: An e-Delphi study. Rehabilitation Department, Erasmus University Medical Centre, Rotterdam, The Netherlands.
- 155.** McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023, October 20–21). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: An e-Delphi study. World Ability Sport Conference (Virtual).
- 156.** Morgan, P. (2021, June). Pain and fatigue in adults with cerebral palsy. CP-Achieve Cooperative Research Centre Conference (Virtual).
- 157.** Morgan, P. (2022, January 25). Professor Prue Morgan – Adults with cerebral palsy: Clinical teaching tips [Podcast]. A Neuro Physio Podcast.
- 158.** Morgan, P. (2022, May). Maximising lifespan mobility in adults with cerebral palsy. Australian Physiotherapy Association THRIVE Conference (Virtual).
- 159.** Morgan, P. (2022, October). Physical health of adults with cerebral palsy. Australian Physiotherapy Association Virtual Conference.
- 160.** Morgan, P. (2024, June 27). Navigating transitions: Optimizing physiotherapy care across the lifespan in developmental disability. Universiti Kebangsaan Malaysia, Bangi, Malaysia
- 161.** Morgan, P. (2024, March). Barriers and facilitators to health and disability service access experienced by people with cerebral palsy – An Australian perspective. Royal College of Surgeons in Ireland, Dublin, Ireland.
- 162.** Morgan, P. (2024, March). Enhancing lifespan care for people with cerebral palsy: Insights from Australia. Queen’s University Belfast, Belfast, Northern Ireland.
- 163.** Morgan, P. (2024, March). Enhancing lifespan care for people with cerebral palsy: Insights from Australia. Queen’s University Belfast, Belfast, Northern Ireland.
- 164.** Morgan, P. (2024, March). Enhancing lifespan care for people with cerebral palsy: Insights from Australia. University of Michigan, Ann Arbor, United States.
- 165.** Morgan, P. (2025, June 24–26). Emergency department presentations of falls and injuries in people with cerebral palsy: A cohort study. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) & 4th
- Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD): World Congress on Childhood-Onset Disabilities, Heidelberg, Germany.
- 166.** Morgan, P., & Ding, J. (2025, June 24). National Disability Insurance Scheme: Effecting policy change, improving lives. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) & 4th Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD): World Congress on Childhood-Onset Disabilities, Heidelberg, Germany.
- 167.** Morgan, P., & Kozelj, N. (2025, June 24–26). Being participation-focused: What are effective strategies that support participation? 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) & 4th Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD), Heidelberg, Germany.
- 168.** Morgan, P., & Reedman, S. (2022, April). Maximising physical activity participation opportunities and measuring physical participation outcomes [Webinar]. Adult and Aging Special Interest Group of the Australasian Academy of Cerebral Palsy and Developmental Medicine.
- 169.** Morgan, P., & Soh, S. (2025, October 23–25). Falls-related hospital admissions in adults with cerebral palsy – Par for the course? Australian Physiotherapy Association Scientific Conference 2025, Adelaide, Australia.
- 170.** Morgan, P., & Zanudin, A. (2025, June 24–26). Exploring the characteristics and utilization of General Practice healthcare by adults with cerebral palsy: A systematic review. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) & 4th Triennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD): World Congress on Childhood-Onset Disabilities, Heidelberg, Germany.
- 171.** Morgan, P., Cleary, S., Dutia, I., Bow, K., & Shields, N. (2023, May 24–27). Community-based physical activity interventions for adolescents and adults with complex cerebral palsy: A scoping review investigating implementation and safety. 35th Annual Meeting of the European Academy of Childhood-onset Disability (EACD), Ljubljana, Slovenia.
- 172.** Morgan, P., Holmes, C., & Costley, W. (2024, November). MyCP Guide – Cerebral palsy and premature ageing (podcast).
- 173.** Morgan, P., Imms, C., Cleary, S., Kilgour, G., & Hickey, L. (2025, June). Being participation-focused: Implementing the evidence to support young people with cerebral palsy to participate in meaningful life situations. 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) & 4th Triennial Meeting of the International Alliance of Academies of Childhood

- Disability (IAACD): World Congress on Childhood-Onset Disabilities, Heidelberg, Germany.
- 174.** Morgan, P., Kozelj, N., Kilgour, G., & Imms, C. (2024, July). Participation in health care by young adults with cerebral palsy: Exploring relationships among attendance, involvement and associated health conditions. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 175.** Morgan, P., Pool, D., & Thornton, A. (2024, July 31–August 3). NDIS characteristics and utilisation by individuals with cerebral palsy. The ResearchWorks Podcast at the 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia. <https://www.youtube.com/watch?v=u0E-UnavBO8>
- 176.** Morgan, P., Shepherd, D., & Reddihough, D. (2025, April 4). What can health service data tell us about healthcare use in people with cerebral palsy? 2025 CP-Achieve & Australasian Academy of Cerebral Palsy and Developmental Medicine Cerebral Palsy Symposium: Progress and Possibilities, Melbourne, VIC, Australia.
- 177.** Morgan, P., Tang, K., & Imms, C. (2024, July 31–August 3). National Disability Insurance Scheme: An evaluation of plan size, access and use by people with cerebral palsy. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 178.** O’Shea, A., & Walsh, M. (2021, June 17–18). Milkshakes and cups of tea: Talking about consent with people with intellectual disability and complex communication needs. Australasian Society for Intellectual Disability (ASID) Conference (Virtual).
- 179.** O’Shea, A., Topaz, S., Walsh, M., Devèze, T., & Kerr, S. (2023). Relationships, intimacy, and sexuality expert panel [Online panel]. Life Without Barriers
- 180.** Pennacchia, J. (2022, August). Assessing the mental health of young people with complex communication needs [Webinar]. AGOSCI. <https://www.agosci.org.au/>
- 181.** Pennacchia, J. (2022, June). How do people with complex communication needs tell us about their mental health and wellbeing? [Webinar]. YouTube. <https://www.youtube.com/watch?v=wzh6emQLudU>
- 182.** Pennacchia, J. (2022, September 8). Assessing mental health in young people with complex communication needs: A PhD update. CHILD Autumn Conference, Jönköping, Sweden.
- 183.** Pennacchia, J. (2023, April 19). Assessing mental health in young people with complex communication needs: Project update and consumer perspectives [Webinar]. CP-Achieve Webinar Series. <https://www.youtube.com/watch?v=SexewcSMPJs>
- 184.** Pennacchia, J. (2023, August 3). “We need teams!” (Bright Lights PhD in 3). CP-Achieve & AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 185.** Pennacchia, J. (2024, October). Assessing mental health in people with communication support needs – Who does it and how? AGOSCI Webinar Series. <https://www.agosci.org.au/>
- 186.** Pennacchia, J., et al. (2023, September 14–15). “It’s more complex than rocket science!” Melbourne Children’s Campus Student Symposium, Melbourne, Australia.
- 187.** Pennacchia, J., et al. (2024, May 15–16). Measuring mental health in children with disability. Karolinska Institutet–UNICEF Joint Conference on Global Child & Adolescent Mental Health, Stockholm, Sweden.
- 188.** Pennacchia, J., et al. (2024, May). Assessing mental health in young people with complex communication needs: Who’s role and how? 36th Annual Meeting of the European Academy of Childhood Disability (EACD), Bruges, Belgium.
- 189.** Pennacchia, J., et al. (2024, May). Screening and assessment tools to measure mental health in people with complex communication needs: A systematic review. 36th Annual Meeting of the European Academy of Childhood Disability (EACD), Bruges, Belgium.
- 190.** Pennacchia, J., et al. (2025, April). Clinician perspectives on what is needed to better assess the mental health of young people with complex communication needs. CP-Achieve & AusACPDM Symposium: Progress and Possibilities – Celebrating 5 Years of Research Through Lived Experience and Planning the Future, Melbourne, VIC, Australia.
- 191.** Pennacchia, J., Imms, C., Bonyhady, G., Wong, S., Pacheco, C., Coghill, D., & Granlund, M. (2023, November 10). “We need teams!” – Clinician perspectives on what is needed to better assess the mental health of young people with complex communication needs. 2023 Child Health Research Symposium, Perth Children’s Hospital, Perth, Australia
- 192.** Pennacchia, J., Imms, C., Bonyhady, G., Wong, S., Pacheco, C., Coghill, D., & Granlund, M. (2024, May). “We need teams!” Clinician perspectives on what is needed to better assess the mental health of young people with complex communication needs. 36th Annual Meeting of the European Academy of Childhood Disability (EACD), Bruges, Belgium.
- 193.** Pennacchia, J., Reddihough, D., Imms, C., Wallen, M., Morgan, P., Coghill, D., Shields, K., Novak, I., Boyd, R., Sakzewski, L., Bradford, M., Fahey, M., Morgan, C., & Spittle, A. (2024, July 31). Infinite Horizons – Babies to Adults with Cerebral Palsy, Real People to AI Advancements. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 194.** Pennacchia, J., Walsh, M., & Imms, C. (2024, August). Enhancing the participation of people with communication disabilities in research by optimising informed consent processes. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 195.** Plummer, J., Cleary, S., & Holmes, C. (2023, August 3–4). Fitness for life. Fitness for everyone. CP-Achieve & AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 196.** Quartermaine, J., Rose, T., Auld, M., & Johnston, L. (2023, September 10–13). Factors impacting positive and negative participation of young people with cerebral palsy: A Delphi study of consumers and health professionals. 77th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPD), Chicago, USA.
- 197.** Reddihough, D., et al. (2024, July 31). Infinite Horizons: A workshop for everyone – Babies to adults with cerebral palsy, real people to AI advancements. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 198.** Rutz, E., Graham, K., Holmes, C., & Thomason, P. (2023, August 3–4). Musculoskeletal issues: What we don’t talk about. CP-Achieve & AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 199.** Sawyer, S. M., & Walsh, M. (2025, April 3). Discussions about sexual health with adolescents with cerebral palsy: Who says what, to whom, and when? 2025 CP-Achieve & AusACPDM Symposium: Progress and Possibilities – Celebrating 5 Years of Research Through Lived Experience and Planning the Future, Melbourne, VIC, Australia.
- 200.** Scheinberg, A., Imms, C., Knight, S., Toovey, R., & Saloojee, G. (2022, March 1–5). Debate: Therapists are redundant: As we move to participation-focused model of care, will evidence-based therapy be required? Australasian Academy of Cerebral Palsy and Developmental Medicine / International Alliance of Academies of Childhood Disability (AusACPDM/IAACD) 2022: Better Together (Virtual).
- 201.** Shields, N. (2023). Research Works Podcast, European Academy of

- Childhood-onset Disability (EACD) Edition, Day 3.
- 202.** Shields, N. (2023, February). Victorian Diversity Inclusion and Leisure Forum. Aquatics and Recreation Victoria, Melbourne, Australia
- 203.** Shields, N., Bhowon, Y., Willis, C., Taylor, N., Mudiyansele, S. B., Watts, J., Imms, C., & Prendergast, L. (2023, May 19). Effect of a community-based intervention (FitSkills) for young people with disability on physical activity participation: A stepped wedge cluster randomised trial. International Cerebral Palsy Symposium, Belfast, Northern Ireland.
- 204.** Smith, M., & Smith, N. (2023, October 1). Co-designing pain assessment for children and young people with cerebral palsy. Pain Education Day: "Knowledge Mobilisation: Taking Evidence Outside the Box," Pain in Child Health (PICH), Halifax, Nova Scotia, Canada.
- 205.** Smith, M., Smith, N., Thirumanickam A., & Harvey, A. (2024, April 21–24). Pain assessment for children and young people with cerebral palsy. 45th Annual Scientific Meeting of the Australian Pain Society, Darwin, Northern Territory, Australia.
- 206.** Smith, N. (2023, September 11). Chronic pain assessment for young people with CP. Kids Rehab Western Australia, Australia.
- 207.** Smith, N. (2024, August 1). A core outcome set of chronic pain assessment tools for young people with cerebral palsy: Consensus from key stakeholders. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia
- 208.** Smith, N. (2024, August 1). Multidimensional pain experience in children before and one to two years following selective dorsal rhizotomy. 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 209.** Smith, N. (2024, March). Co-designing chronic pain assessment for young people with cerebral palsy. CP-Achieve Webinar Series.
- 210.** Smith, N. (2024, March). Development of the COS of chronic pain assessment tools. Research Works Podcast.
- 211.** Smith, N. (2024, November 5). A core outcome set of chronic pain assessment tools for young people with cerebral palsy: Consensus from key stakeholders. Child and Adolescent Health Service Research Symposium, Perth, Australia.
- 212.** Smith, N. (2025, April 11). Development of a core outcome set and decision tree to assess chronic pain in young people with cerebral palsy. Australian Pain Society (APS) 2025 Conference, Pain in Child Health (PICH) Trainee Rapid-Fire Presentations, Melbourne, Australia.
- 213.** Smith, N., & Ostojic, K. (2022, November 7). Chronic pain assessment and management in cerebral palsy. Australian Physiotherapy Association Online Lecture.
- 214.** Smith, N., Gibson, N., Imms, C., Thornton, A., & Harvey, A. (2025, June). Pilot implementation of an evidence-based decision tool to guide assessment of chronic pain for young people with cerebral palsy. 26th European Academy of Childhood-onset Disability & International Alliance of Academies of Childhood Disability Conference, Heidelberg, Germany.
- 215.** Smith, N., Smith, M., Gibson, N., Bear, N., Thornton, A., Imms, C., & Harvey, A. (2023, October 1–4). The development of a tool to rate the feasibility of chronic pain outcome measures in children with cerebral palsy. International Symposium on Pediatric Pain (ISPP), Halifax, Nova Scotia, Canada.
- 216.** Smithers-Sheedy, M. (2023, September). Evaluation of a mindfulness-based stress reduction intervention for adults with cerebral palsy with anxiety and/or emotion regulation difficulties. 77th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AAPDM), Chicago, USA.
- 217.** Stead, V., Walsh, M., Cook, O., & Caluya, G. (2024). 'Vulnerable populations': Ethics for research with minorities. Deakin University's Gender and Sexuality Research Network, Online
- 218.** Thevarajah, A. (2023, March 2). Adapted bicycle riding outcomes for children and adolescents with disabilities [Audio podcast episode]. In DMCN Journal Podcast. Mac Keith Press. <https://www.podbean.com/media/share/pb-xgeqp-1322167>
- 219.** Thevarajah, A., Wallen, M., Imms, C., Lonsdale, C., Carey, J. J., & Froude, E. H. (2023, June 2–4). Impact of adapted bicycle riding on outcomes for children and adolescents with disabilities: A systematic review. World Physiotherapy Congress, Dubai, United Arab Emirates.
- 220.** Wallen, M. (2021, May 13). Consumer engagement: How to develop partnerships with consumers in research. Australian Catholic University, School of Behavioural & Health Sciences Research Forum, Australia.
- 221.** Wallen, M. (2023, October 7). Consumer involvement: The why, how, when, and who of developing partnerships with consumers in research and practice. IGNITE 2023: Australian Physiotherapy Association Conference, Brisbane, Australia
- 222.** Wallen, M., Walsh, M., Harman, I., Manning, P., Ponza, B., Wong, S., Shaw, B., Sellwood, D., Anderson, K., & Reddihough, D. (2024, July 30–August 4). A framework and toolkit for inclusive research with people with cerebral palsy who use alternative and augmentative communication (AAC). 12th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM): Respect, Respond & Re-imagine, Cairns, Australia.
- 223.** Walsh, M. (2021, June 17–18). PhD in 3. Collaborate, Innovate, Achieve: CP-Achieve & AusACPDM Joint Symposium 2021, Murdoch Children's Research Institute, Melbourne, Australia (Virtual).
- 224.** Walsh, M. (2021, June 17–18). Sexuality, self-esteem and silence: What adolescents with cerebral palsy (CP) and complex communication needs (CCN) aren't able to say about sex. Collaborate, Innovate, Achieve: CP-Achieve & AusACPDM Symposium, Murdoch Children's Research Institute, Melbourne, Australia (Virtual).
- 225.** Walsh, M. (2021, November 29). Conversations about sexuality, romance and gender when you have cerebral palsy and complex communication needs [Webinar]. CP-Achieve Webinar Series (Virtual). <https://www.youtube.com/watch?v=OGSPHHA4pLg>
- 226.** Walsh, M., & Mitchell, C. (2021, July 28). "The best PD we've ever had" – What we learned from creating, delivering, and refining an AAC workshop series for parents and carers [Webinar]. AGOSCI Member Webinar Series.
- 227.** Walsh, M., Anderson, K., Watson, J., Sawyer, S., O'Shea, A., & Stead, V. (2023, July 24–27). Redefining vulnerability with research participants who use AAC – A useful framework. International Society for Augmentative and Alternative Communication (ISAAC) Conference, Cancún, Mexico.
- 228.** Walsh, M., Manning, P., Advisory Group, Anderson, K., O'Shea, A., Sawyer, S., & Watson, J. (2025, March). Understanding communication about sexuality for adolescent AAC users with cerebral palsy. AGOSCI 2025 Conference, Adelaide, Australia.
- 229.** Walsh, M., Manning, P., Pacheco, C., Watson, J., Anderson, K., Sawyer, S., O'Shea, A., & Advisory Group. (2025, March). Navigating sexuality support for adolescents with cerebral palsy who use AAC: Perspectives, challenges, and key themes. AGOSCI 2025 Conference, Adelaide, Australia.
- 230.** Walsh, M., Manning, P., Wong, S., Watson, J., Anderson, K., O'Shea, A., & Sawyer, S. (2023, December 4–5). Participatory methods for research with young people with cerebral palsy and complex communication needs about sexuality: "I want more words about penis vagina sex relationships." De-centring Academic Expertise: The Politics of Knowledge Production and Social Transformation, The Australian Sociological Association (TASA), Critical Disability Studies, Emotions and Affect, and Applied Sociology, University of Melbourne & online.
- 231.** Walsh, M., Mitchell, C., Watson, J., Anderson, K., & Greene, L. (2023, July 24–

27). Coaching and empowering carers in AAC through a group program.

International Society for Augmentative and Alternative Communication (ISAAC) Conference, Cancún, Mexico.

**232.** Walsh, M., Pacheco, C., Anderson, K., O'Shea, A., Sawyer, S., Brant, B., Hogan, A., Manning, P., Wong, S., & Watson, J. (2024, May 29–June 1). "Where's the guidebook?": How parents of young people who use augmentative and alternative communication (AAC) talk about sexuality with their young people. 36th Annual Meeting of the European Academy of Childhood Disability (EACD), Bruges, Belgium.

**233.** Walsh, M., Pacheco, C., Anderson, K., Watson, J., Sawyer, S., O'Shea, A., & Advisory Group. (2025, March). Including AAC users in conversations about their own lives: What we learned from carrying out a research study with young people with cerebral palsy who use AAC. AGOSCI 2025 Conference, Adelaide, Australia.

**234.** Walsh, M., Stead, V., O'Shea, A., Sawyer, S., Watson, J., & Anderson, K. (2023, December 4–5). In pursuit of ethical and inclusive research: What ethics committees and disability researchers can learn from each other in research on sensitive topics. De-centring Academic Expertise: The Politics of Knowledge Production and Social Transformation, The Australian Sociological Association (TASA), Critical Disability Studies, Emotions and Affect, and Applied Sociology, University of Melbourne & online.

**235.** Walsh, M., Wong, S., Ponza, B., Harman, I., Manning, P., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024, May 29–June 1). "Take the time to get to know us": A framework and toolkit for inclusive research with people with cerebral palsy who use alternative and augmentative communication (AAC). 36th Annual Meeting of the European Academy of Childhood Disability (EACD), Bruges, Belgium

**236.** Zhao, H., Karlsson, P., Kavehei, O., & McEwan, A. (2021, October). Reflections from engineers, people with cerebral palsy and caregivers. IEEE SENSORS 2021 Conference, Sydney, Australia.



*Dr Jane Tracey, CP-Achieve Associate Investigator; Oliver Hunter, CP-Achieve Consumer Partner; Peta Hooke; Dr Lyndal Hickey, CP-Achieve Associate Investigator; Evelyn Culnane, CP-Achieve Associate Investigator, speaking at the CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia*



*Associate Professor Margaret Wallen, CP-Achieve Chief Investigator; Claire Rowland, CP-Achieve Knowledge Translation Fellow; and Gaurav Thakkar, CP-Achieve Consumer Partner, speaking at the CP-Achieve and AusACPDM 2025 Cerebral Palsy Symposium: Progress and Possibilities, Melbourne, Australia*

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We sincerely thank the members of our Stakeholder Advisory Group and other Advisory Groups for their time, commitment, and valuable contributions. Their thoughtful advice and continued support have been integral to the development and delivery of CP-Achieve.

**Thank you for being part of our journey so far. Together, we're making a difference—and the future holds even more promise.**