

CP-ACHIEVE
ANNUAL
REPORT
2023-2024



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A message from Dinah Reddihough

CP-Achieve Principal Investigator



It gives me pleasure to introduce the 2023-2024 Annual Report for CP-Achieve. The breadth and depth of work has been truly inspiring and made possible by a dedicated team of consumer advisors and researchers working together to ensure meaningful outcomes.

Our vision is an Australia where people with cerebral palsy receive the best health care throughout their lives – not just in childhood – and live in, and contribute to, supportive communities that enable their participation. In this report, you can read about the many projects that are being undertaken by CP-Achieve's committed team in partnership with our consumers and their families. Much of the work has been published and presented at national and international forums. A real sense of community has developed between consumers, their families, researchers and students. This was showcased at the Symposium held in August of 2023.

As we approach the conclusion of CP-Achieve, we know that much more needs to be done. Fortunately, a significant number of doctoral and postdoctoral students have been trained to continue the work alongside their senior colleagues, and some have received grants to undertake new projects. Together we will continue to strive and advocate to improve the lives of all people with cerebral palsy. We need everyone's ongoing support to achieve this aim.

Thank you again to all our consumers, their families, students, postdoctoral researchers, research associates, investigators and staff, for your amazing contribution and with special thanks to Debora Markelis who has compiled this report.

Dinah S. Reddihough

Steering Committee

CP-Achieve's Steering Committee directs and governs the program. It is made up of the principal investigator, two program leaders, four theme leaders, and members of the operational team



Dinah Reddihough
Principal Investigator
Chair



Christine Imms
Participation Theme
Leader



David Coghill
Program 1 Leader



Nora Shields
Workforce Theme
Leader



Prue Morgan
Program 2 Leader



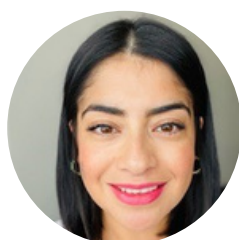
Margaret Wallen
Consumer Involvement
Theme Leader



Carolyn Pinto
Consumer Coordinator



Rob Carter
Economics Theme
Leader



Debora Markelis
Research Coordinator &
Executive Support

Our team

CP-Achieve's projects are led by our Chief Investigators and Associate Investigators who work across several projects

Principal Investigator

| Dinah Reddihough

Program 1

David Coghill

Program 1 Leader, CI

Kerr Graham, CI

Susan Sawyer, CI

Evelyn Culnane, AI

Gabrielle Drake, AI

Leanne Johnston, AI

Jane Tracy, AI

Lyndal Hickey, AI

Sarah Giles, Postdoctoral

Research Fellow

Carlee Holmes, Postdoctoral

Research Fellow

Program 2

Prue Morgan

Program 2 Leader, CI

Ingrid Honan, CI

Bruce Bonyhady, AI

Mats Granlund, AI

Jan Willem Gorter, AI

Peter Rosenbaum, AI

Stacey Cleary, Postdoctoral

Research Fellow

Gaela Kilgour, Honorary Fellow

Iain Dutia, Honorary Fellow

Georgia McKenzie, Knowledge

Translation Fellow- Physical

Activity

Themes

Nora Shields

Specialist Workforce

Theme Leader, CI

Margaret Wallen

Consumer Involvement

Theme Leader, CI

Christine Imms

Participation

Theme Leader, CI

Rob Carter

Health Economics

Theme Leader, CI

Consumer Involvement and Operational Team

Carolyn Pinto

Consumer Involvement

Coordinator Families

Sevastine Katsakis

Consumer Involvement

Coordinator Young

People

Claire Rowland

Consumer Involvement

Knowledge Translation

Fellow

Debora Markelis

Research

Coordinator

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, Loretta Sheppard, Michelle McInerney, Petra Karlsson, Rachel Toovey, Sue Reid, Utsana Tonmakuyakul*, Ximena Camacho

**Also an Associated Higher Degree Research Student*

Higher Degree Research Students

CP-Achieve Postdoctoral Candidates

Georgia McKenzie (completed), Jacinta Pennacchia, Jacqueline Ding, Megan Walsh, Nadine Smith

Associated Higher Degree Research Students

Katie Headrick, Rowan Johnson, Kerry Britt, Magnus Ivarsson

Our themes & programs

THEMES

Promotion of Participation

Health Economics

Developing a Specialist Workforce

Consumer Involvement

PROGRAMS

Program 1

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

Projects

- Estimate prevalence of physical and mental health problems
- Understand health service use and outcomes
- Determine impact on participation in education, employment and community
- Evaluate the outcomes of transition services for young people with cerebral palsy
- Evaluate impact of screening on the identification of mental health problems

Program 2

Building supportive family, community and health service environments which help young people take part in life situations which are important to them

Projects

- Expand available exercise evidence to those with complex disability
- Adapt an evidence-based lifestyle program to the Australian context
- Understand the needs and perspectives of people with cerebral palsy and their families
- Create pathways from rehabilitation to recreation
- Translate available participation-focused intervention evidence to the Australian context

Theme highlights

Outcomes across our programs are maximised by four embedded themes focusing on participation, health economics, specialist workforce, and consumer involvement

Promotion of Participation

Participation at CP-Achieve refers to being present and actively involved in various life situations, including the home, school, community, and healthcare environments. A key objective of CP-Achieve is to support meaningful participation that fosters physical fitness, recreation, and social and community connections, while also empowering individuals to manage their own health. We believe that through active involvement, individuals develop a stronger sense of self-efficacy and form lasting preferences for healthy living-factors that contribute to improved physical and mental well-being and overall life satisfaction.

HIGHLIGHTS

- Rohan Symonds, a research collaborator and Consumer Advisor on CP-Achieve's Project TEAM, was awarded a Churchill Fellowship to travel to Boston and Florida. During his visit, he met with our Project TEAM collaborators and gathered insights to support the translation and adaptation of the program for the Australian context.
- Christine Imms, a Chief Investigator was awarded the Robert Hill memorial lectureship from the British Columbia Children's Hospital in Vancouver, Canada to speak about participation, and participation in research as an important life situation for young people with cerebral palsy and their families.
- The participation theme team also co-produced a paper for a special edition of the journal *Childhood*, describing our experiences and learnings from working together as co-researchers.

Health Economics

The health economics theme at CP-Achieve supports the research team in understanding current health needs and identifying the most effective strategies for achieving meaningful change. By combining clinical expertise with assessments of cost-effectiveness, this theme helps ensure that improvements in health and wellbeing are delivered in a way that maximises value and impact.

HIGHLIGHTS

- Provided ongoing guidance through the CP-Achieve Steering Committee, research programs, project meetings, and support for various grant applications.
 - Maintained active involvement in the data linkage project.
 - Continued support for the upper limb orthoses clinical trials.
 - Advised on the cost analysis component of the Bike Riding project as part of a PhD student's research.
-

Developing a Specialist Workforce

Ensuring that individuals with cerebral palsy receive the highest quality healthcare throughout their lives requires a strengthened and expanded workforce with the right expertise and capabilities. This theme focuses on developing a skilled multidisciplinary clinical and research workforce with expertise in adolescent and young adult cerebral palsy. Our goals include training high-calibre doctoral researchers, supporting postdoctoral fellows to build immediate research capacity, translating new knowledge into practice through dedicated fellowships, and offering education and training opportunities for professionals working in cerebral palsy and related fields.

HIGHLIGHTS

- Continued to support the training and development of five doctoral students and three postdoctoral research fellows.
 - Appointed two Knowledge Translation Fellows to lead the implementation of new knowledge into practice, with a focus on consumer involvement in research and community-based physical activity for young people with cerebral palsy.
 - Delivered a cerebral palsy symposium in partnership with the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPD), providing multidisciplinary scientific education for health professionals and promoting excellence in research and evidence-based clinical care.
 - Continued to host a monthly webinar series featuring presentations from postdoctoral research fellows, chief investigators, associate investigators, research associates, and leading experts in cerebral palsy research and practice.
 - Awarded travel scholarships to eight CP-Achieve postdoctoral research fellows and affiliated PhD students, as well as six consumer research partners, enabling them to present at national and international conferences, share research findings, foster collaboration, and engage in professional development.
-

Consumer Involvement

CP-Achieve remains strongly committed to embedding consumer involvement across all aspects of our research. In 2023–24, CP-Achieve advisory groups met regularly with researchers and investigators to share their valuable lived experience, ensuring our work remains meaningful and relevant to young people with cerebral palsy and their families.

Beyond advisory group meetings, many consumers also contributed as advisers to individual research projects. These roles provided opportunities for consumers to engage with research areas closely aligned with their personal experiences and interests, further enriching the relevance and impact of our work.

HIGHLIGHTS

- Consumers were actively involved in the CP-Achieve and AusACPDM Cerebral Palsy Symposium held in August 2023. Their contributions included session planning, delivering presentations, participating in panel discussions, and engaging as enthusiastic audience members throughout the two-day event.
- New members were recruited to the Parent Advisory Group to enhance representation and ensure a broader pool of parents is available to contribute as consumer advisers across individual research projects.
- A Consumer Involvement Knowledge Translation Fellowship was established to translate the resources and knowledge developed through CP-Achieve into practice. Over 12 months, the fellowship will identify key lessons in consumer involvement and determine how best to share these insights to maximise their impact on disability research.
- The Consumer Involvement team contributed to the review of the National Health and Medical Research Council's Statement on Consumer and Community Involvement in Health and Medical Research (2016), offering CP-Achieve's expertise to strengthen how consumer involvement principles and practices are defined and applied.

Advisory Groups

Group	Members	Key Achievements
Parent Advisory Group	Comprises parents of young people with a range of cerebral palsy types and severities.	<ul style="list-style-type: none"> • Contribution to an international collaboration to update the definition of cerebral palsy. • Involvement as advisers across a wide range of research projects, involving physical health, mental health, health literacy, NDIS participation, and the evaluation of consumer involvement in CP-Achieve.
One Group, Our Voice	Group of people with cerebral palsy who use AAC (alternative and augmentative communication).	<ul style="list-style-type: none"> • Produced presentations and a publication describing a framework for involving augmentative and alternative communication (AAC) users in research as participants and research partners. • Contribution to an international collaboration on updating the definition of cerebral palsy. • Development of an Inclusive Research Toolkit, providing knowledge, skills and resources to support researchers to include people who use AAC in research as participants and consumers.
CP-Voice	Adolescent advisory group comprising of young people with cerebral palsy aged 10-18 years.	<ul style="list-style-type: none"> • Continued to engage and provide input into research projects as needed.
CP-Unite	Young adult advisory group comprising of young people with cerebral palsy aged 18-30 years.	<ul style="list-style-type: none"> • Continued to provide input into improving physical and mental health and building supportive environments research projects. • Members were involved as advisers across a wide range of research topics including exercise in complex disability, adapting evidence-based lifestyles, participation, pathways from rehabilitation to recreation, transition, and understanding needs and perspectives of people with cerebral palsy and their families.

Our Postdoctoral Research Fellow Highlights

CP-Achieve aims to train high quality postdoctoral researchers to create a new workforce in the field of adolescent and young adult cerebral palsy research



Stacey Cleary

Stacey is a postdoctoral research fellow working on projects focusing on the measurement of participation experiences of adolescents and young adults with cerebral palsy across key life situations, and co-designing lifestyle modules ('CP-Pathfinding') to enhance knowledge and develop the skills of young adults with cerebral palsy in key life areas.

HIGHLIGHTS

- Awarded two seeding grants to pilot the first CP-Pathfinding modules- 2023 Healthy Trajectories Seed Grant (\$29,166) and 2023 Australian Physiotherapy Association Physiotherapy Research Foundation Seed Grant (\$12,000).
- Author on a book chapter focusing on the transition to adult healthcare for young adults with cerebral palsy.
- Developed a webinar for My CPguide with CP-Achieve researchers and consumer experts.



Carlee Holmes

Carlee is a postdoctoral research fellow working on projects focusing on Motorized Movement Therapy in non-ambulant adults with cerebral palsy, CP-Achieve participant characteristics and physical and mental health survey, and lifestyle modules.

HIGHLIGHTS

- Awarded two grants for Motorised Movement Therapy in non-ambulant adults with cerebral palsy project- Cerebral Palsy Alliance Emerging Researcher Grant (\$99,528) and St Vincent's Hospital Research Endowment Fund Grant (\$16,000).
- Author on two book chapters focusing on the transition to adult healthcare for young adults with cerebral palsy, and physical management for neurological conditions.



Sarah Giles

Sarah is a postdoctoral research fellow working on projects aimed at improving the mental health of young people with cerebral palsy, with a focus on analysing CP-Achieve participant characteristics, the Physical and Mental Health Survey, and a mental health screening initiative designed to help clinicians identify coexisting mental health conditions in individuals with cerebral palsy.

HIGHLIGHTS

- Launched the physical and mental health survey.
- Continued to lead a systematic review examining the prevalence of mental health issues in young people with cerebral palsy.
- Led the development of a mental health screening project, including establishing a research collaboration agreement with St Vincent's Hospital and partnering with members of the CP-Achieve Parent Advisory Group to develop a grant proposal.

Our PhD Candidates & Affiliated Higher Degree Research Students

CP-Achieve has supported a number of PhDs as part of the Developing a Specialist Workforce Theme. As the Centre of Excellence progresses, our PhD and affiliated PhD students are finalising their studies and progressing to positions in cerebral palsy related fields.



Jacqueline Ding,
Monash University

Project : Exploring young adulthood: Experiences and perceptions of participation for those with cerebral palsy

Supervisors: Professor Prue Morgan, Dr Stacey Cleary

HIGHLIGHTS

- Publication of two PhD studies in Developmental Medicine and Child Neurology (DMCN) and Disability & Rehabilitation.
- A commentary about the qualitative paper in DMCN.
- Health literacy systematic review paper selected as one of the 'top 10 articles' for 2023-2024 by the American Academy for Cerebral Palsy and Developmental Medicine Lifespan Care Committee.
- Delivery of five presentations within CP-Achieve and two national conferences.



Jacinta Pennacchia,
University of Melbourne

Project : Assessing the mental health of

young people with complex communication needs

Supervisors: Professor Christine Imms, Professor Dave Coghill, Professor Mats Granlund

HIGHLIGHTS

- New Researcher Grant awarded from Speech Pathology Australia.
- Study trip to Sweden, Belgium, and Italy to attend and present at conferences and visit collaborating researchers.
- Completion and submission of systematic review.



Nadine Smith,
Murdoch Children's Research Institute

Project: Pain measurement for all young people with cerebral palsy: A best practice bio-psychosocial model

Supervisors: Professor Christine Imms, Associate Professor Adrienne Harvey, Dr Ashleigh Thornton, Dr Noula Gibson

HIGHLIGHTS

- Presentation of chronic pain workshop at the Australian Pain Society annual

scientific meeting in Darwin.

- Invited published commentary for DMCN.



Megan Walsh
MCRI, Deakin University

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

Supervisors: Professor Susan Sawyer, Dr Jo Watson, Dr Kate Anderson, Dr Amie O'Shea

HIGHLIGHTS

- Publication on ethics co-authored with former chair of ethics committee.
- Development of Inclusive Research Toolkit and publication about development of the toolkit, co-authored with other CP-Achieve researchers including consumer research partners.
- Presentations at European Academy of Childhood-onset Disability (EACD) on the parent arm of research and on the Inclusive Research Toolkit.

Celebrating Success: Completing the PhD Journey



Georgia McKenzie,
La Trobe University

Project : Facilitating community based physical activity in the gym for young adults with cerebral palsy

Supervisors: Professor Nora Shields, Dr Claire Willis, Dr Rachel Kennedy

I'm Georgia, a physiotherapist and researcher with CP-Achieve. In 2024 I completed my PhD which aimed to understand the factors influencing community gym participation for young adults with cerebral palsy.

My PhD journey started from my physiotherapy work with young adults with cerebral palsy at the St Vincent's Hospital Young Adult Complex Disability Service, Melbourne. Many young adults I worked with understood the importance of being active, but found it harder to be active as adults, particularly in their local communities. I wanted to know why this was the case and what could be done to improve the situation.

My PhD included four projects. We reviewed the research to see what work had already been done in this topic. We interviewed young adults with cerebral palsy about their experiences in the gym and interviewed gym staff about how they currently support people with disability. We also surveyed young adults, families, gym staff and health professionals about what ideas might improve participation in the gym.

The physical environment was an important consideration for adults with cerebral palsy, but it was the social aspects – having the right supports, having a sense of belonging, and finding something challenging or fun – that were most important to being active. At the gym, most support was provided once someone was already attending. There was a gap in helping people with disability to ‘get in the door’ in the first place. We found there was a need for health professionals and gyms to work together better to support the transition into local gyms.

I have been fortunate to be able to progress this work after my PhD as a Knowledge Translation Fellow with CP-Achieve. In this role, I am working with a team of young adults with cerebral palsy to co-design physical activity resources. We hope these can support adults with cerebral palsy to navigate community based physical activity in adulthood and share the stories of what is possible.

Affiliated CP-Achieve Higher Degree Research Students

John Carey (PhD), University of Melbourne

Project: CycLink: Linking young people with disability to community participation in cycling

Supervisors: Dr Rachel Toovey, Dr Alicia Spittle, Professor Christine Imms, Professor Nora Shields

Abby Thevarajah (PhD), Australian Catholic University

Project: An investigation and evaluation of an adapted bike program for children 4 to 18 years with disabilities

Supervisors: Professor Elspeth Froude, Dr Margaret Wallen, Professor Christine Imms, Professor Chris Lonsdale

James Czencz (PhD), Australian Catholic University

Project: Evaluating exercise inter-

ventions to improve activity, participation and quality of life for those living with complex forms of cerebral palsy

Supervisors: Professor Peter Wilson, Professor Christine Imms, Professor Nora Shields, Dr Margaret Wallen.

Katie Headrick (PhD), Australian Catholic University

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

Supervisors: Dr Margaret Wallen, Dr Elise Woodman, Professor Christine Imms.

Utsana Tonmakuyakul (PhD), Deakin University

Project: Preference-based quality of life measurement in children with cerebral palsy

Supervisors: Professor Suzanne Robinson, Emeritus Professor Rob Carter, Professor Cathy Mihalopoulos, Professor Dinah Reddiough, Associate Professor Gang Chen

Jacinta Quartermaine (PhD), University of Queensland

Project: Participation experiences of young people with cerebral palsy

Supervisors: Associate Professor Leanne Johnston, Dr Tanya Rose, Dr Megan Auld

Magnus Ivarsson (PhD), Linköping University

Project: Are we measuring mental health problems in young people with developmental disabilities the wrong way?

Supervisors: Professor Henrik Danielsson, Professor Christine Imms, Associate Professor Lena Almqvist, Assistant Professor Lina Homman.

Kerry Britt (PhD), University of Melbourne

Project: ENVISAGE-SP: Creating opportunities to change how service providers think, talk about and approach childhood disability.

Supervisors: Professor Christine Imms, Dr Sarah Knight, Ms Bridget O'Connor, Ms Rose Babic.

Rowan Johnson (PhD), Curtin University

Project: Mobile health technology for home and school therapy program prescription.

Supervisors: Dr Sian Williams, Prof Daniel Gucciardi, Dr Noula Gibson, Dr Becky White

Emily Moore (PhD), University of South Australia

Project: Giving children with cerebral palsy and complex communication needs (CCN) agency to self-report their pain.

Supervisors: Associate Professor Adrienne Harvey, Dr Carolyn Berryman, Professor Lorimer Moseley, Dr Abi Thirumanickam.

CP-Achieve Project Progress

CP-Achieve projects have continued to progress and deliver outcomes with many nearing their final stages of research and outputs

Program 1

PHYSICAL AND MENTAL HEALTH

Prevalence of health problems & issues

- Two surveys continue to recruit to understand young people with cerebral palsy and their physical and mental health.
- Measurement properties and feasibility of chronic pain assessment tools for use with children and young people with cerebral palsy project completed (PhD).
- Development of a core outcome set of chronic pain assessment tools for young people with cerebral palsy project completed and pilot implementation at Perth Children's Hospital underway (PhD).
- Conversations about sexuality for adolescents with cerebral palsy and CCN systematic review submitted and data analysis underway (PhD).
- Systematic review to understand the prevalence and nature of mental health conditions in young people with cerebral palsy continues.

Understanding health service use and outcomes

- Project using National Prescribing Service Medicinewise database to determine General Practitioner involvement with people with cerebral palsy continues.
- Major data linkage study between Australian Institute of Health & Welfare databases and the Victorian Cerebral Palsy Register to determine use of a range of health services is ongoing.
- An exploration of National Disability Insurance Scheme (NDIS) plan size, access and use by people with cerebral palsy via publicly available data project completed.
- National Disability Insurance Agency (NDIA) unit record data project conducting data analysis.
- Scoping review exploring the profile of general practice access and interventions among adults with cerebral palsy continues.
- Health service utilisation by people ageing with cerebral palsy project commenced.

Impact on participation in education, employment & community

- Data analysis continues for a survey to identify participation in key life situations.

Evaluate the outcomes of transition services for young people with CP

- Transition to independent living project analysing data and writing up results.
- GP health pathways to support general practitioners to care for adults with cerebral palsy published.
- Quality improvement project for transition and services for adults with cerebral palsy commenced.
- Collaboration with Monash Health, Victoria to promote the introduction of a new Disability Access Health Service run by the Centre for Developmental Disability Health for adults with disabilities established.
- Development of checklists for adults with cerebral palsy and practitioners working with them is in progress.

Evaluate impact of screening on the identification of mental health problems

- Mental health screening project commenced.
- A randomised control trial of mindfulness for adults with anxiety completed and published.
- Current practice and future needs of the workforce involved in identifying mental health concerns in young people with CCN project continuing (PhD).
- The experiences of and language used by AAC-users when communicating about mental health project commenced (PhD).
- Systematic review of instruments measuring wellbeing in people with complex disability completed (PhD).

Program 2

BUILDING SUPPORTIVE ENVIRONMENTS

Exercise in complex disability

- Feasibility study looking at home-based motorised cycling in non-ambulant adults with cerebral palsy completed and published.
- Funding received and project commenced for a pilot study investigating cardiometabolic biomarkers, health and wellbeing outcomes for motorised movement therapy in non-ambulant adults with cerebral palsy.
- Online survey of current practices in adaptive cycling among providers in Australia completed and published (PhD).
- Evaluation of the online training program CHAIN (Cycling through Health coaching, Adaptation, Inclusion and Networks) project continues (PhD).
- Adapting experience-based co-design to disability research: co-producing the CycLink Co-design study completed, write up in progress (PhD).
- Using an experience-based co-design process to develop principles of a community cycling program (CycLink) in progress (PhD).
- A mixed method evaluation of the CycLink Co-design Study data analysis underway.
- Project looking at the Freedom Solutions Ready Set Ride adapted bike training program detailing implications for children and adolescents with disabilities completed and written-up (PhD).
- Feasibility study of the Ready Set Ride adapted bike training program designed for children and adolescents with disabilities aged 5 to 18 years commenced (PhD).
- Qualitative study exploring the wants and needs of adults with complex cerebral palsy for community based physical activity is completing data analysis with preliminary findings presented internationally.

- Feasibility project of Fitskills for young adults with cerebral palsy who use wheeled mobility- key community partnerships established and recruitment completed.

Adapting an evidence-based lifestyle program to Australian context

- Evidence-based lifestyle program scoping review continues.
- A mixed methods systematic review to synthesise what is known about how young adults with cerebral palsy develop health literacy completed and published (PhD).
- Funding received and project commenced for the co-design of web-based educational module focused on enhancing health literacy (CP-Pathfinding: Your Health) (PhD).
- Funding received and project commenced for the 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.

Creating pathways from rehabilitation to recreation

- Qualitative study looking at industry perspectives on the implementation of social support for young adults with disability in community gyms completed and submitted for publication.
- Knowledge Translation Fellowship focusing on co-designing resources to support community based physical activity for adults with cerebral palsy who use wheelchairs commenced.

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

- Analysis of publicly available National Disability Insurance Scheme data to understand capacity building goals in young people with cerebral palsy in Australia study completed and manuscript prepared.
- Qualitative study designed to explore 'young adulthood' via the perspectives of young people with cerebral palsy completed (PhD).
- Experience of participation in daily life scoping review manuscript completed and submitted for publication.

Translating available participation-focused intervention evidence to the Australian context

- Adapting and evaluating feasibility of Pathways and Resources for Engagement and Participation (PREP) project developed 'The Young Adult Supplement to PREP' for publication.
- CEval – Consumer involvement evaluation project completed and publication submitted.

Consumer involvement

- A scoping review of evaluation tools and outcomes to evaluate consumer involvement in cerebral palsy research underway.
- Evaluation of the involvement of people with cerebral palsy and complex communication needs as research partners with CP-Achieve study continues.
- Funding secured and planning in progress for a project looking at the process, authenticity and impact of consumer involvement in CP-Achieve's program.
- Evaluation of the mentor program for young adult research partners' project completed.
- State Trustees funded project to increase involvement of people with cerebral palsy and complex communication needs within CP-Achieve and more broadly completed.
- Consumer Involvement Knowledge Translation Fellow commenced.

Year in review

CP-Achieve has continued to make an impact with our team disseminating research findings, securing awards and funding for ongoing and future research.

CP-Achieve reach

8

Webinars held with over 162 attendees

1,089

Newsletter subscribers

2,817

Social media followers

Publications & presentations

69

Presentations, talks & podcasts (national, international & online platforms)

27

Publications, articles & book chapters published

4

Consumers presented at national & international conferences

Grants received

6

External grants awarded to CP-Achieve researchers totaling \$175,222

- 2023 New Researcher Grant from Speech Pathology Australia- Jacinta Pennacchia
- 2023 Healthy Trajectories Seed Grant- Stacey Cleary
- 2023 Australian Physiotherapy Association Physiotherapy Research Foundation Seed Grant-Stacey Cleary
- 2023 Cerebral Palsy Alliance Emerging Researcher Grant- Carlee Holmes
- 2023 St. Vincent's Hospital Research Endowment Fund Grant - Carlee Holmes
- Australian Group Supporting Communication Inclusion (AGOSCI) 2023 Research Grant- Megan Walsh

CP-Achieve & AusACPDM 2023 Symposium

CP-Achieve has continued the strong ethos of learning, development and leadership across Australia and internationally, by holding a bi-annual cerebral palsy symposium in Melbourne on 3-4 August 2023.

Partnership with AusACPDM

This year, we once again partnered with the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) to deliver our second joint symposium. This has been a significant partnership for CP-Achieve as AusACPDM aims to provide multidisciplinary scientific education for health professionals and to promote excellence in research and best practice clinical care for children and adults with cerebral palsy and developmental conditions.

Symposium aims & areas of focus

The symposium theme of 'Linking Health, Wellbeing and Participation' sought to explore and share new knowledge about maximising health, participation and social opportunities for adolescents and young adults living with cerebral palsy.

The symposium focused on life situations that young people with cerebral palsy had told us are important, including healthcare, home life, education and employment, fitness for life, relationships and friendships, and community participation. Topics were aligned with the two major aims of CP-Achieve- improving physical and mental health and building supportive family, community, and health service environments.

Symposium outcomes

The symposium was a great success, featuring informative and engaging speakers, well-structured sessions, valuable networking opportunities, and a strong focus on translating knowledge related to young adults with cerebral palsy. Each session was enriched by a strong consumer voice, with young people with cerebral palsy and their supporters sharing their insights and lived experience.

number of sessions	19 sessions were delivered across the two days
number of presenters	70 researchers, experts and people with lived experience presented their work
total registrations	170 researchers, people with lived experience, health providers, policy makers, researchers, and representatives from non-government organisations, hospitals, and professional peak bodies from across the country and internationally, attended the two day event

Research outputs

CP-Achieve continues to be a highly productive team, working in collaborations that have contributed to evidence based best practice information and literature

Publications, articles & book chapters

1. 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), 5523. <https://doi.org/10.3390/jcm12175523>
2. 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/>
3. Clough, I., Culnane, E., & Loftus, H. (2024). Exploring the transition experiences of young adults with cerebral palsy. *Child: care, health and development*, 50(1), e13186. <https://doi.org/10.1111/cch.13186>
4. Czencz, J., Shields, N., Wallen, M., Wilson, P. H., McGuckian, T. B., & Imms, C. (2023). Does exercise affect quality of life and participation of adolescents and adults with cerebral palsy: a systematic review. *Disability and rehabilitation*, 45(25), 4190–4206. <https://doi.org/10.1080/09638288.2022.2148297>
5. Ding, J. Y., Cleary, S. L., & Morgan, P. E. (2024). Participation experiences of young people with cerebral palsy in key life situations: A qualitative study. *Developmental medicine and child neurology*, 66(10), 1369–1379. <https://doi.org/10.1111/dmcn.15920>
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26. Walsh, M., Stead, V., Sawyer, S. M., O'Shea, A., Watson, J. M., & Anderson, K. L. M. (2024). In Pursuit of Ethical and Inclusive Research: What Ethics Committees and Disability Researchers Can Learn From Each Other. *International Journal of Qualitative Methods*, 23. <https://doi.org/10.1177/16094069241237549>

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Presentations, talks & podcasts

- Carey, J., et al. (2023, October 5–6). Exploring barriers and facilitators to participation in outdoor adapted cycling for young people with disability: Providers' perspectives [Conference presentation]. IGNITE Conference, Annual Australian Physiotherapy Association Conference, Brisbane, Australia.
- Carey, J., et al. (2024, May 29–June 1). Researching co-design together: Developing an experience-based co-design study protocol [Poster presentation]. European Academy of Childhood Disability (EACD) 36th Meeting, Bruges, Belgium.
- Carey, J., et al. (2023, October 5–6). Delivering adapted cycling interventions for young people with disability in Australia: Who's doing what? [Conference presentation]. IGNITE Conference, Annual Australian Physiotherapy Association Conference, Brisbane, Australia
- Carey, J., et al. (2024, May 29–June 1). Using co-design as a route towards cycling participation: Development of intervention principles [Conference presentation]. European Academy of Childhood Disability (EACD) 36th Meeting, Bruges, Belgium.
- Carey, 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 & Participation, Melbourne, Australia.
- Carey, J. (2023, August 3–4). Cycling is for everyone: Adaptive cycling for young people with cerebral palsy functioning at GMFCS Level IV and V [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 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/>
- 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
- 9.** Cleary, S., Willis, C., & Shields, N. (2023, October 24). The effects of community-based physical activity interventions on adolescents and young adults with disability: A systematic review and meta-analyses of randomised controlled trials [Poster presentation]. Murdoch Children's Research Institute Symposium, Melbourne, Australia.
- 10.** Coghill, D. (2023, August 3–4). Cerebral Palsy and Mental Health [Keynote address]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 11.** Culnane, E. (2023, September 10–13). From Pond to Sea – Are we doing enough to ensure the best lifelong outcomes for our patients? [Conference presentation]. Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ) 6th Annual Scientific Meeting, Hobart, Australia.
- 12.** Czencz, J. (2023, October 20–21). Exploring the wants and needs of adults with cerebral palsy who use wheelchairs for community-based physical activity [Conference presentation]. 2023 World Abilitysport Conference on Physical Activity for Health for People with Cerebral Palsy and other Neurological Conditions, Edinburgh, Scotland.
- 13.** Czencz, J. (2023, October 3). Let's Get Active! Exploring the wants and needs of adults with cerebral palsy who use wheelchairs for community-based physical activity [Conference presentation]. Cerebral Palsy Scotland Conference, Scotland.
- 14.** Czencz, J. (2023, October). Research update – Promoting exercise for adults with CP [Seminar presentation]. Central Remedial Clinic, Dublin, Ireland.
- 15.** Czencz, J. (2023, July). Unleashing the potential of adults with complex CP through community-based physical activity [3MT presentation]. Australian Catholic University, Australia.
- 16.** 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, Australia.
- 17.** 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 [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 18.** 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 [Poster presentation]. Murdoch Children's Research Institute Symposium, Melbourne, Australia.
- 19.** Ding, J., Cleary, S., & Morgan, P. (2024, May 22). Exploring young adulthood: Experiences of those with cerebral palsy [Webinar]. CP-Achieve Webinar Series [Online].
- 20.** 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 [Webinar]. European Academy of Childhood Disability (EACD) 36th Meeting 2023 Awards Celebration Event.
<https://www.eacd.org/2023-awards-celebration>
- 21.** Giles, S. (2023, August 3–4). Cerebral palsy and mental health: Where are we now and initiatives to improve wellbeing [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 22.** Giles, S. (2023, August 3–4). Parents and wellbeing [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 23.** Graham, K., Rutz, E., Holmes, C., & Thomason, P. (2023, August 3–4). Musculoskeletal issues: What we don't talk about [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 24.** Harvey, A. (2023, October 1–4). Pain in children and young people with cerebral palsy: Challenges and solutions [Plenary speaker]. International Symposium on Pediatric Pain (ISPP), Halifax, Canada.
- 25.** Harvey, A., Smith, N., Smith, M., Doyle, C., & Hogan, A. (2023, August 3–4). Chronic pain assessment for children and young people with CP [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 26.** Harvey, A., Smith, N., Smith, M., Doyle, C., & Hogan, A. (2023, October 1–4). Co-designing pain assessment for children and young people with CP [Conference presentation]. International Symposium on Pediatric Pain, Halifax, Nova Scotia, Canada.
- 27.** Hickey, L., Harms, L., Reddihough, D., Imms, C., Culnane, E., & Saunders, V. (2024, May 15–16). Families' perspectives on transitioning young adults with cerebral palsy to independent living [Conference presentation]. Universitas21 Community of Practice Inaugural Conference, Virtual event.
- 28.** Holmes, C. (2023, November 21–23). Transforming the health and wellbeing of people with complex disabilities through motorised cycling [Conference presentation]. Oceania Seating Symposium, Melbourne, Australia.
- 29.** Holmes, C. (2023, October 20–21). Transforming the health and wellbeing of people with complex disabilities through motorised cycling [Conference presentation]. World Ability Sport Conference (Hybrid event), Edinburgh, Scotland.
- 30.** Holmes, C. (2024, April 24). CP-Achieve participant characteristics survey: Physical, mental, and sexual health [Webinar]. CP-Achieve Webinar Series [Online].
- 31.** Holmes, C., Fredrickson, E., Saunders, V., & Murphy, D. (2023, August 3–4). Pathways between education and employment [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health,

Wellbeing & Participation, Melbourne, Australia.

- 32.** Holmes, C., & Rowe, A. (2023, November 21–23). What is happening under the covers? Bed positioning assessment and goal setting [Conference presentation]. Oceania Seating Symposium, Melbourne, Australia.
- 33.** Imms, C. (2023, September). 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.
- 34.** Imms, C. (2023, July 29–30). Participation for everyone: Reaching ultimate outcomes [Conference presentation]. 6th National Conference of the Australian ADHD Professionals, Melbourne, Australia.
- 35.** 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 [Online].
- 36.** McKenzie, G. (2023, November 30). 'More confident within myself' [Webinar]. Disability Sport and Recreation Victoria, International Day of People with Disability (Online), Victoria, Australia.
- 37.** McKenzie, G. (2023, August 3–4). 'PhD in 3' [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing & Participation, Melbourne, Australia.
- 38.** McKenzie, G. (2023, August 3–4). Creating inclusive gym environments [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 39.** 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 [Conference presentation]. World Ability Sport Conference [Online].
- 40.** 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 [Conference presentation]. World Ability Sport Conference [Online].

- 41.** Morgan, P. (2024, March). Barriers and facilitators to health and disability service access experienced by people with cerebral palsy – An Australian perspective [Guest lecture]. Royal College of Surgeons Ireland, Dublin, Ireland.
- 42.** Morgan, P. (2024, March). Enhancing lifespan care for people with cerebral palsy: Insights from Australia [Guest lecture]. Queen's University, Belfast, Northern Ireland.
- 43.** Morgan, P. (2024, March). Enhancing lifespan care for people with cerebral palsy: Insights from Australia [Guest lecture]. University of Michigan, Ann Arbor, USA.
- 44.** Morgan, P. (2024, June 27). Navigating transitions: Optimizing physiotherapy care across the lifespan in developmental disability [Workshop]. Universiti Kebangsaan Malaysia.
- 45.** O'Shea, A., Topaz, S., Walsh, M., Devèze, T., & Kerr, S. (2023). Relationships, intimacy, and sexuality expert panel live [Online panel]. Life Without Barriers.
- 46.** Pennacchia, J. (2023, August 3–4). "We need teams!" (Bright Lights PhD in 3) [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 47.** Pennacchia, J., et al. (2023, September 14–15). "It's more complex than rocket science!" [Conference presentation]. Melbourne Children's Campus Student Symposium, Melbourne, Australia.
- 48.** Pennacchia, J., et al. (2023, November 8–10). "We need teams!" – Clinician perspectives on what is needed to better assess the mental health of young people with complex communication needs [Conference presentation]. Perth Children's Hospital Child Health Research Symposium, Perth, Australia.
- 49.** Pennacchia, J., et al. (2024, May 29 – June 1). "We need teams!" – Clinician perspectives on what is needed to better assess the mental health of young people with complex communication needs

[Conference presentation].

- European Academy of Childhood Disability (EACD) 36th Meeting, Bruges, Belgium.
- 50.** Pennacchia, J., et al. (2024, May 29 – June 1). Assessing mental health in young people with complex communication needs: Who's role and how? [Poster presentation]. European Academy of Childhood Disability (EACD) 36th Meeting, Bruges, Belgium.
- 51.** Pennacchia, J., et al. (2024, May 15–16). Measuring mental health in children with disability [Conference presentation]. Karolinska Institute–UNICEF Joint Conference on Child and Adolescent Mental Health, Stockholm, Sweden.
- 52.** Pennacchia, J., et al. (2024, May 29 – June 1). Screening and assessment tools to measure mental health in people with complex communication needs: A systematic review [Conference presentation]. European Academy of Childhood Disability (EACD) 36th Meeting, Bruges, Belgium.
- 53.** Plummer, J., Cleary, S., & Holmes, C. (2023, August 3–4). Fitness for life. Fitness for everyone [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 54.** 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 [Conference presentation]. 77th Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine, Chicago, USA.
- 55.** Rutz, E., Graham, K., Holmes, C., & Thomason, P. (2023, August 3–4). Musculoskeletal issues: What we don't talk about [Conference presentation]. CP-Achieve and AusACPDM 2023 Symposium: Linking Health, Wellbeing and Participation, Melbourne, Australia.
- 56.** Smith, M., & Smith, N. (2023, October 1). Co-designing pain assessment for children and young people with cerebral palsy. In Pain Education Day, "Knowledge mobilisation: Taking Evidence Outside the Box", Pain in Child

Health (PICH) [Conference presentation]. Halifax, Nova Scotia, Canada.

57. Smith, M., Smith, N., Thirumanickam, A., & Harvey, A. (2024, April 21–24). Pain assessment for children and young people with cerebral palsy. Australian Pain Society 45th Annual Scientific Meeting [Conference presentation]. Darwin, Northern Territory, Australia.

58. Smith, N. (2023, September 11). Chronic pain assessment for young people with CP. Kids Rehab Western Australia [Presentation]. Western Australia, Australia.

59. Smith, N. (2024, March). Co-designing chronic pain assessment for young people with cerebral palsy. CP-Achieve webinar series [Webinar].

60. Smith, N. (2024). Development of the COS of chronic pain assessment tools. Research Works Podcast [Podcast episode].

61. 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 [Conference presentation]. Halifax, Nova Scotia, Canada.

62. 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 panel].

63. Wallen, M. (2023, October 7). Consumer involvement: The why, how, when, and who of developing partnerships with consumers in research and practice. Australian Physiotherapy Conference IGNITE2023 [Conference presentation]. Brisbane, Australia.

64. 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 Conference [Conference presentation]. Cancun, Mexico.

65. 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." In De-centring academic expertise: The politics of knowledge production and social transformation [Conference presentation]. The Australian Sociological Association (TASA), Critical Disability Studies, Emotions and Affect and Applied Sociology, University of Melbourne & online, Melbourne, Australia.

66. 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 Conference [Conference presentation]. Cancun, Mexico.

67. 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. European Academy of Childhood Disability (EACD) 36th Meeting [Conference presentation]. Bruges, Belgium.

68. 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. In De-centring academic expertise: The politics of knowledge production and social transformation [Conference presentation]. The Australian Sociological Association (TASA), Critical Disability Studies, Emotions and Affect and Applied Sociology, University of Melbourne & online, Melbourne, Australia.

69. Walsh, M., Wong, S., Ponza, B., Harman, I., Manning, P., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024, 29 May– 1 June). "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). European Academy of Childhood Disability (EACD) 36th Meeting [Conference presentation]. Bruges, Belgium.

Thank you

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Partners

CP-Achieve is carried out in partnership with the following organisations:



