



CP-ACHIEVE
**ANNUAL
REPORT**

2021/2022






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MESSAGE FROM DINAH REDDIHOUGH



It gives me great pleasure to share with you the annual CP-Achieve report. **Our vision** is an Australia where people with CP receive the best health care throughout their lives – not just in childhood – and live in, and contribute to, supportive communities that enable their participation. Work in this area is crucial. Whilst there has been much important work done to improve outcomes for children with cerebral palsy, there has been little research into how best to assist adolescents and adults. Fortunately, this situation is beginning to change with researchers internationally beginning to address the issues faced by adults with cerebral palsy. CP-Achieve is making an important contribution to these efforts and our work is being shared nationally and internationally.

As we complete our third year of CP-Achieve, I would like to thank all our consumers, their families, students, postdoctoral researchers, research associates, investigators and staff, for their amazing contribution to the work that is being undertaken to improve the lives of adolescents and young adults with cerebral palsy. Much has been achieved over this reporting period. I hope that you will enjoy reading about some of the accomplishments of our committed team.

ABOUT CP-ACHIEVE

CP- Achieve is a National Health and Medical Research Council (NHMRC) funded Centre of Research Excellence that supports collaborative research and development in cerebral palsy (CP) research. The program is funded for 5 years and commenced in February 2020.

We are a team of national and international researchers, adolescents and young adults with cerebral palsy, families, clinicians, and students.

Together we are working on research and finding ways to help adolescents and young adults with CP live a full and healthy life and participate in life situations which are important to them.

What is CP-Achieve?

What does CP-Achieve do?

CP-Achieve does research aiming to support people with CP aged 10 to 30 years to achieve good health, access to excellent health services, and to participate in relationships, work, leisure, physical activity and the community.

There are four important themes that underpin all the work CP-Achieve does and two main programs of research. Each program conducts several research projects.

Together our projects will help us understand

- The physical and mental health problems of young people with CP
- What outcomes are important to young people

This information can help us

- Develop programs to be used by health and disability providers to assist young people
- help young people participate in health and community services that meet their needs
- Understand the costs of services that work
- Inform policy and practice

PROGRAMS AND THEMES

PROGRAMS

1

IMPROVING THE PHYSICAL AND MENTAL HEALTH OF ADOLESCENTS AND YOUNG ADULTS WITH CEREBRAL PALSY

2

BUILDING SUPPORTIVE FAMILY, COMMUNITY AND HEALTH SERVICE ENVIRONMENTS WHICH HELP YOUNG PEOPLE TAKE PART IN LIFE SITUATIONS WHICH ARE IMPORTANT TO THEM

PROJECTS

- Estimate prevalence of physical and mental health problems
- Victorian-based birth cohort of adults with CP follow up
- 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 CP
- Evaluate impact of screening on the identification of mental health problems

- 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 CP and their families
- Create pathways from rehabilitation to recreation
- Translate available participation- focused intervention evidence to the Australian context

THEMES

Promoting Participation

Health Economics

Developing a Specialist Workforce

Consumer Involvement

STEERING COMMITTEE

CP-Achieve is overseen by a Steering Committee comprised of theme and program leads, members of the operational team and a chairperson.



Dinah Reddihough
Principal Investigator
(Chair)



Christine Imms
Participation Theme
Leader



Rob Carter
Economics Theme Leader



Margaret Wallen
Consumer Involvement
Theme Leader



Nora Shields
Workforce Theme Leader



David Coghill
Program 1 Leader



Prue Morgan
Program 2 Leader



Joan Gains
Community Coordinator



**Research Coordinator
(Executive Support)**
Kari Klein / Deb Markelis
(Jul- Feb) (Mar-Jun)

OUR TEAM



DINAH REDDIHOUGH

Principal Investigator



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

Iain Dutia, Postdoctoral
Research Fellow

Robbie Eres, Postdoctoral
Research Fellow



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



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



JOAN GAINS

Consumer
Involvement
Coordinator



**SEVASTINE
KATSAKIS**

Consumer
Involvement Project
Assistant



**KARI KLEIN
(JUL- FEB)**

Research Coordinator



**DEB MARKELIS
(MAR-JUN)**

Research Coordinator

RESEARCH ASSOCIATES

Abby Thevarajah*, Adam Scheinberg, Adrienne Harvey, Barry Rawicki, Dana Anaby, Gina Hinwood, Helen Bourke-Taylor, Ian Wong, James Czencz*, Jessica Kramer, Jocelyn Cohen, John Carey*, Kathleen Ooi, Loren Apokourastos*, Loretta Sheppard, Melissa Mulraney, Michelle McInerney, Petra Karlsson, Rachel Toovey, Reece Adams, Sue Reid, Utsana Tonmakuyakul*, Ximena Camacho

*Also a CP-Achieve and associated higher degree research student

CP-ACHIEVE AND ASSOCIATED HIGHER DEGREE RESEARCH STUDENTS

Georgia McKenzie, Jacinta Pennacchia, Jacinta Quartermaine, Jacqueline Ding, Katie Headrick, Rowan Johnson, Kerry Britt, Magnus Ivarsson, Megan Walsh, Nadine Smith

OUR ADVISORY GROUPS

CP-Achieve has a number of advisory groups that provide input and direction to our program of work.

Stakeholder Advisory Group

Our Stakeholder Advisory Group includes key personnel from major non-government organisations involved in the care of people with disability and aims to improve the applicability and quality of research, knowledge translation for end-users and outcomes for young people with CP and their families

Members: Nadia Badawi, Melissa Boekhoorn, Anne-Marie Dickinson, Kerry Evans, Adrienne Fosang, Christine Imms, Sevastine Katsakis, Kate McCrae, Andrew Pope, Anna Perini, Dinah Reddihough, Scott Sheppard, Amy Southwood, Maria Velegrinis, Rob White

Consumer Advisory Groups

Our Consumer Advisory Groups provide input into our research projects by sharing their advice and expertise. This way we can make sure our research is the best it can be for young people with CP. We have three Consumer Advisory Groups.

CP Unite: Young adult advisory group with 10 advisors

Members: Alesia Lu, Nicole Kozeli, Alana Jovanovski, Greg Bonyhady, Rohan Symonds, Gaurav Thakkar, Cassandra Assaad, Shanee Holmwood, Abbey Potter

CP Voice: Adolescent advisory group with 7 members

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

Parent Advisory Group: 10 members

Members: Toni Green, Kylie Brown, Bianca Brant, Janine Stanley, Helen Briffa, Chris Pacheco, Michelle King, Ebonie Gough, Meg Smith, Wendy Pritchard

CP-ACHIEVE THEMES AND HIGHLIGHTS

CP-Achieve's themes of promoting participation, economic evaluation, developing a specialist workforce, and consumer involvement underpin all the work that is carried out in the program.

Promotion of Participation

Promoting participation is one of the cross-cutting themes of CP-Achieve. We define participation as attending and being involved in life situations. Life situations are activities or collections of activities that are relevant to the individual, their family or community, and occur in home, school, community - including paid and voluntary work - and health care settings. By attending, we mean 'being there' either physically or virtually (in online environments) in the desired or needed activities and settings. By involvement, we mean the experience of participation while attending. A sense of involvement can be gained through what you do, how you feel or your thinking/engagement with the activity or setting. It is personal. You need to be able to attend specific life situations to be involved (if you are not there, you can't be involved). But it is possible to 'attend' with very limited involvement. Both elements are important.

Young people with CP are known to experience participation restrictions in many aspects of life. Our theme goals are to understand how best to help young people with CP achieve active participation to: build fitness, provide recreation, promote meaningful social and community conn-

ections, increase workforce participation and support self-management of health needs wherever possible. The Participation Theme team provides information and guidance to researchers across CP Achieve about how to study and assess participation.

Research Highlights

- Co-designed a participation survey for use by Program 1 to evaluate participation in life situations that CP-Unite, one of our advisory groups comprised of young adults with CP, indicated were important to study. The survey has ethical approval and measures participation attendance, involvement and satisfaction, and the extent to which aspects of the environment act as supports or barriers.
- Developed a proposal to write a Position Paper on 'Being a co-researcher as a means to participation'.
- Planning to write a paper for publication on the process of designing the participation survey.

Health Economics

Health economics is involved with both the *'Improving Physical and Mental Health'* and the *'Building Supportive Environment'* streams of CP-Achieve. The contribution of health economics is to assist researchers in thinking about the most efficient solutions to the issues and problems they are working on. So, in addition to their own expertise in clinical care, this involves researchers thinking about outcomes in relation to cost – that is, whether the intended solution represents 'value-for-money' in the use of a limited budget or whether there are other alternatives where improved health and wellbeing could be obtained.

Research Highlights

- Assistance and advice provided on an ongoing basis through the CP-Achieve Steering Committee, research programs and project meetings, and various grant applications.
- Involvement in successful grant applications – the GYM-SPARC application to VicHealth and the Translational Research Grant from the NSW Department of Health.
- Involvement with two NHMRC grant applications.
- Ongoing involvement with the data linkages project.

- Ongoing contribution to the MedicineWise data analysis project.
- Assisted with finalisation of the two wrist/hand orthoses studies.
- Involvement with the Complex Care hub project and associated activities.
- PhD candidate nearing completion, on the key topic of outcome measurement.

Developing a Specialist Workforce

In CP-Achieve, workforce refers to those working specifically with adolescents and adults in the field of CP.

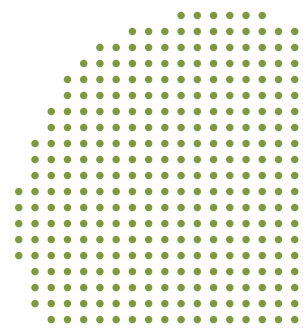
The current health and disability workforce with expertise working with adolescents and adults with CP is very small. This needs to be expanded if we are to realise our vision of people with CP receiving the best health care throughout their lives – not just in childhood – and live in, and contribute to, supportive communities that enable their participation.

To grow a multidisciplinary clinical and research workforce that is knowledgeable and expert in adolescent and young adult CP, we have committed to:

- Training high quality doctoral researchers to create a new workforce
- Supporting postdoctoral fellows to develop immediate research capability
- Disseminating our new knowledge via translation fellowships
- Providing education, training and networking opportunities to support clinicians and researchers who work in CP and closely related areas

Research Highlights

- Workforce creation by training doctoral students. Four full time PhD scholarships have been funded.
- Workforce development by training postdoctoral research fellows. Four positions have been funded across health economics, mental health, physical health and lifestyle programs.
- Multidisciplinary education program. We have continued to offer a program of education and training opportunities to support clinicians and researchers and to extend the reach of CP-Achieve, including monthly webinar series to showcase the work of our doctoral students, postdoctoral fellows, Chief Investigators, Associate Investigators and Research Associates.

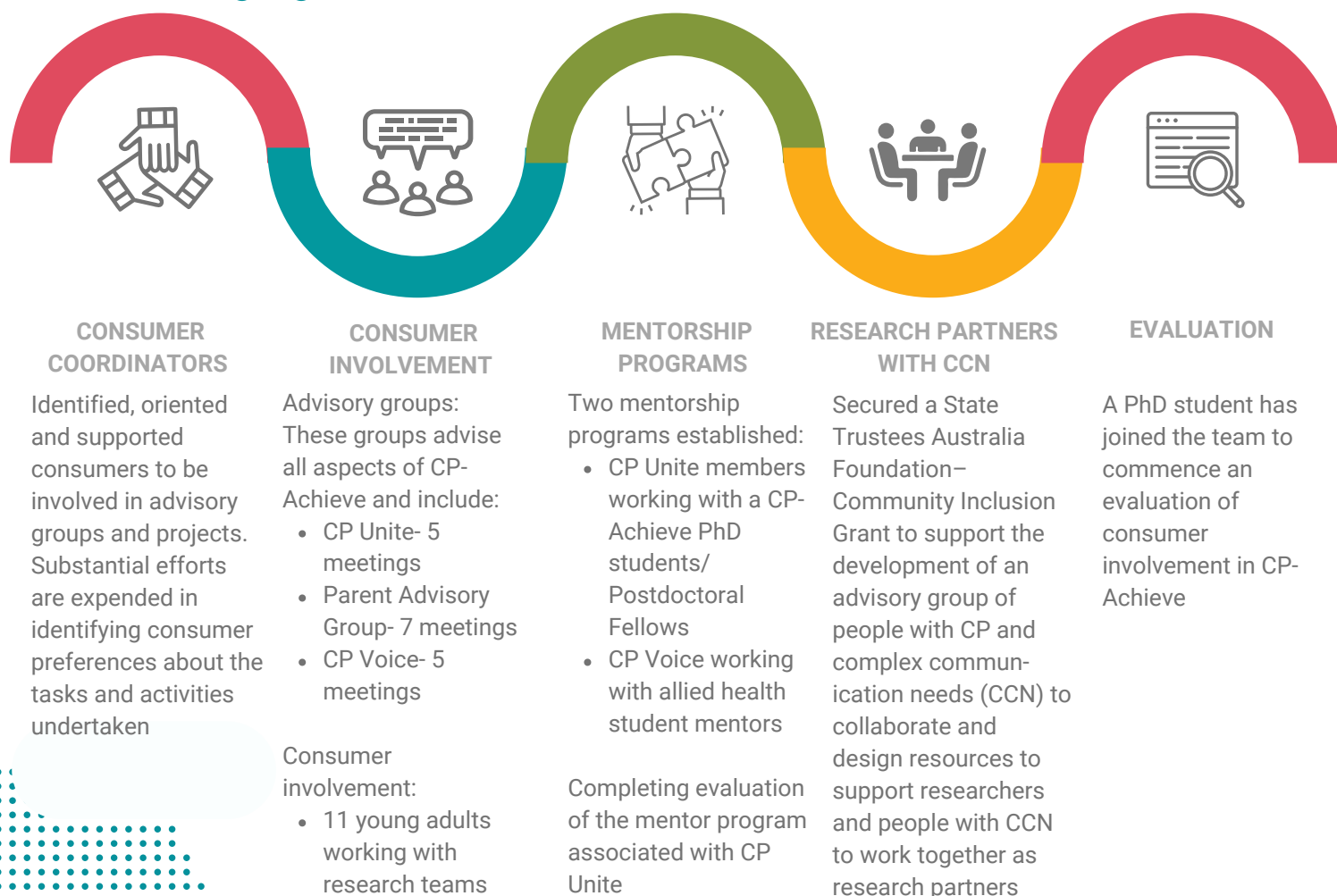


Consumer Involvement

CP-Achieve is committed to involving people with lived experience in all research activities – that is, adolescents and young adults with CP, and their families. Our research is more meaningful, applicable and effective in achieving its aims when we co-design research with these consumers. Working together has enriched the research and researchers, both professionally and personally.

CP-Achieve employs two staff as consumer coordinators, both with lived experience of CP and disability who are able to authentically support consumers to be involved. Our researchers continue to embrace consumer involvement and consumers are working in all research teams.

Research Highlights



Outcomes for CP-Achieve Research Partners

Some of the aims of consumer involvement were to optimise outcomes for young people with CP and their families through the research completed and translated by CP-Achieve, as well as maximising efficiency of research dollars and other resources invested in CP-Achieve. An additional aim was that research partners would also benefit professionally and personally from their involvement.

Reflections from advisors

A recent CP Unite meeting sought reflections from advisors. These clustered in two themes:

- *Theme 1: Advisors making an impact*

Advisors making an impact. CP Unite advisors believed they make an impact by sharing their lived experiences and advocacy for what is important for young people with CP. They highlighted contributions on transition to adulthood, mental health, and optimising the accessibility of language in communications with research participants.

- *Theme 2: What involvement means to advisors*

Advisors reported being proud to make a difference, that they developed more confidence and benefited by a strong sense of collegiality with the CP Unite group. Some quotes from our advisors:

"I was inspired to find my spark and discover potential avenues of study within the disability advocacy sector."

"I am also honoured to be a part of an advisory team that values each other and their experiences no matter how similar or different they are"

"CP-Achieve has changed my life, I am now more willing to connect, learn, and advocate for others through every aspect of my involvement."

OUR POSTDOCTORAL RESEARCH FELLOWS

CP-Achieve is committed to workforce development and supports a number of Post Doctoral Research Fellows by providing training in research, knowledge translation and professional skills.

The CP-Achieve Post Doctoral Research Fellows receive supervision and mentorship from members of the CP-Achieve team and external researchers, and have access to a peer network. Their development focuses on using the Allied Health Career Pathways blueprint as a basis for deliberating future career opportunities and optimising the delivery of safe and effective services for young people with cerebral palsy now and into the future.



Stacey Cleary

Dr Stacey Cleary is a research physiotherapist with a keen interest in community-based physical activity and the transition to adulthood for young people with CP.

Stacey's role at CP-Achieve is as a postdoctoral researcher in Team 2 where the focus is on building supportive environments. She has coordinated the weekly writing sessions and peer support for the Higher Degree Research students and is the co-supervisor of one PhD student and three honours students.

This year, Stacey has progressed the scoping review that will synthesise the experiences of participation for young people with CP.

She has also contributed to other CP-Achieve projects based around physical health and exercise. Recently, Stacey led the development and submission of a Medical Research Future Fund (MRFF) grant aimed at early to mid-career researchers and co-led (with Professor Christine Imms) a second MRFF submission targeted at allied health researchers. Both grants included other CP-Achieve postdoctoral fellows, Chief Investigators, and several of our Research Associates.

Sarah is a Postdoctoral Research Fellow at CP-Achieve. Sarah's clinical and research background is in mental health. Her PhD focused on cognitive and emotional functioning in eating disorders. Sarah has worked clinically in a range of health settings including chronic pain and women's health.

Sarah's role as the Postdoctoral Research Fellow lead for Team 1, Mental Health is to oversee the projects which aim to improve the mental health of young people with CP. This is being approached in three main ways: a survey of young people with CP to understand their experiences of anxiety, depression, and how this may impact upon their physical health; a systematic review of the prevalence of mental health issues in young people and adults with CP; and by increasing stakeholder engagement concerning mental health research.

Since joining CP-Achieve, Sarah has been involved in the write up of the results from a mental health literature review, analysis of preliminary responses from consumers in the first *understanding survey*, development of a Stakeholders' Engagement strategy and development of advertising resources to include more engaging content, based on feedback from CP-Unite. Sarah has also commenced running monthly workshops for the CP-Achieve Higher Degree Research group and integrating presentations into Team 1 meetings.



Sarah Giles



Robbie Eres

Dr Robert (Robbie) Eres' expertise largely surrounds the social determinants of health and how social factors, including loneliness and social exclusion, exacerbate mental health symptoms (e.g., social anxiety, depression, stress) and contribute to poor physical health outcomes.

Robbie was a Postdoctoral Research Fellow in Team 1 of CP-Achieve. While with the team, Robbie spearheaded a mental health toolkit that was co-designed with young people with lived experience. He designed, explored and extracted data for a systematic review on mental illness in young people with CP. Robbie also led an opinion piece urging Australian clinicians to establish a specialised mental health service for young people with CP.

Dr Iain Dutia is a lecturer in physiotherapy at Australian Catholic University and a research officer at The University of Queensland, School of Human Movement and Nutrition Sciences.

Iain's role at CP-Achieve in Team 1 is to work with the other postdoctoral research fellows on the focus of enhancing physical and mental health. This year, Iain progressed a systematic review which evaluated the assessment tools used to measure fatigue in people with CP. This review will inform future work on developing ways to help people with CP to manage fatigue. He has also contributed to other CP-Achieve projects based around physical health and exercise, with a focus on people with complex CP.



Iain Dutia



Carlee Holmes

Dr Carlee Holmes is the senior physiotherapist at the Young Adult Complex Disability Service, St Vincent's Hospital Melbourne and a CP-Achieve Postdoctoral Research Fellow. Her PhD focused on postural management of non-ambulant adults.

Carlee's role as a Postdoctoral Research Fellow in Team 1 is to develop the physical health survey with a focus on pain, fatigue and sleep and to further the understanding of the experiences of healthcare for adolescents and young adults.

Since joining the team, Carlee has been involved in the recent MRFF grant application and developed the physical health component of the physical and mental health survey. With her strong passion for improving the health of non-ambulant adults with CP, Carlee has also developed a research protocol investigating the use of a passive cycling device.

OVERVIEW OF PHD ACTIVITIES

CP-Achieve has funded and supported a number of PhDs as part of the Developing a Specialist Workforce Theme.

CP-Achieve PhD Candidates

Jacqueline Ding

Supervisors: Professor Prue Morgan, Dr Stacey Cleary

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

Background: Jacqueline's PhD project looks at understanding the experiences of adolescents and young adults with CP as they transition into adulthood, and some of the barriers/facilitators that have helped them navigate participation in their communities. Some areas of interest include education and employment experiences, navigating the NDIS, relationships with other people (including friendship, romantic and family) and everything in between involved with growing up and becoming an adult. The primary aim of this research project is to capture the lived experiences of young people with CP and to develop resources to support their transition into adulthood. A secondary aim is to raise awareness and change the way this population group (along with other persons with disabilities) are perceived in the wider community.

Progress: This year Jacqueline commenced her candidature and for the first 6 months focused on a combination of background reading, write up of study 1 protocol and obtaining ethics approval which focuses on capturing the experiences and perceptions of adolescents and young adults with CP and how they transition into adulthood. Jacqueline has been busy with recruitment and transcription of interviews. Study 2 has also commenced which is a mixed-methods systematic review of health literacy in young people with CP and its relationship to quality of life. Jacqueline has successfully completed her 6 months milestone review.

Jacinta Pennacchia

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

Project name: Assessing the mental health of young people with complex communication needs

Background: This PhD is driven by the overarching aim of young people with complex communication needs (CCN) being

able to access services to address their mental health concerns in a way that is equitable to their peers. The main outcome of this PhD is the development of a valid and reliable approach to screening and/or assessment of mental wellbeing and mental health problems in young people with CCN.

This is significant because access to valid and reliable instruments are necessary to accurately identify poor mental wellbeing or mental health problems, facilitating appropriate treatment to promote positive mental wellbeing and mitigate against the consequences of mental health problems. In turn, this PhD should contribute to improving young people's access to health funding and services and enable them to contribute to planning their own interventions.

Progress: Jacinta's work to date has involved defining her research questions and planning studies which work towards the overall PhD aim. To do this, Jacinta has been reviewing the current literature and learning relevant research methods. She has written the protocol for a systematic review (Study 1) and will shortly be conducting database searches and article screening. Jacinta has also made progress with consumer involvement, facilitating orientation of advisors who have CP and CCN to CP-Achieve's advisory groups and recruiting three advisors to her project (two young people with CCN and one parent of a child with CCN). This year Jacinta was awarded a research grant from AGOSCI- an inclusive group interested in enhancing the

participation of all people with complex communication needs- to support consumer engagement in this project.

Nadine Smith

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

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

Background: Up to three out of four people with CP experience chronic pain throughout their life. This is higher than the prevalence reported in the general population. Pain burden has been identified as a research priority by people with CP, however it remains under-recognised and poorly assessed in this population. In CP, pain is known to increase with age, severity of gross motor impairment and the presence of dyskinetic motor types. Chronic pain in CP is associated with reduced quality of life, reduced participation and increased mental health disorders such as anxiety and depression. Guidelines for chronic pain assessment for young people with CP that address the different ways chronic pain impacts on a young person and their family, including emotional impact are needed. This research aims to develop and implement a CP specific framework that is meaningful and useful for all people with CP, regardless of their physical, cognitive or communication abilities. A CP specific framework has the potential to improve

routine clinical practice around the identification and assessment of chronic pain for all people with CP. This will facilitate referral to multidisciplinary teams for therapies, including clinical psychology which is considered best practice in other populations with chronic pain.

Progress: Over the past 12 months Nadine has completed a systematic review on measurement properties of pain coping tools for young people with a neurodevelopmental disability using the COSMIN guidelines and worked to obtain ethical approval from all involved ethics committees for the remaining three studies of her PhD. Nadine has successfully completed confirmation of candidature for The University of Western Australia and commenced the second study of her PhD – including adapting a clinical utility tool to make it more specific for CP and building a REDCap database to collect inter-rater reliability data.

Georgia McKenzie

Supervisors: Professor Nora Shields

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

Background: This project aims to (1) identify the factors influencing physical activity and gym participation for young adults with CP, (2) identify and prioritise strategies to improve participation in community gyms, and (3) understand and

develop scalable social support strategies that can be implemented in community gyms across Victoria, in order to facilitate participation for young adults with CP.

Progress: Georgia has published a qualitative study on factors influencing gym participation for young adults with CP and presented findings at the Australasian Academy of CP and Developmental Medicine (AusACPD) 2022 and CP International Sport and Recreation Association (CPIIRA) 2021 conferences. Georgia has also completed a manuscript on the Delphi study identifying and prioritising strategies to improve gym participation from the perspectives of key stakeholders (young adults, families, gym staff and clinicians). Key findings included physically accessible environments, reducing cost barriers, informational support, staff training and 1:1 support in the gym. Georgia has also completed a protocol for her qualitative study investigating gym staff experiences of social support strategies.

Megan Walsh

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

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

Background: Sexuality is central to being human

and during adolescence (between the ages of 10-24 years old), young people are learning about and expressing their sexuality. Adolescents with disabilities like CP face barriers in this area. People with CCN experience an additional set of barriers. There is very little research to help us understand what those barriers are for adolescents with CP and CCN needs, and what supports they might benefit from. What little research there is, has sought the perspectives of parents, support workers, teachers, or therapists rather than adolescents with CP and CCN themselves.

To our knowledge, this is the first study to explore the perspectives of adolescents with CP and CCN about the conversations they have (and want to have) about sexuality. In keeping with CP-Achieve's commitment to consumer involvement in research, this study includes adolescents with CP and CCN in two ways: as research partners on an Advisory Board, and as research participants who can share their opinions.

We know that parents and guardians play an important role in all adolescents' development of sexuality and identity. In this study, there will also be conversations with parents to understand what they need to support their adolescent with CP and CCN in conversations about sexuality.

Progress: This year, Megan has commenced a systematic scoping review and recruited people for a CCN Advisory Board. The Advisory Board consists of adolescents and young adults with CP, with CP and CCN, a sibling of an adolescent with CP and CCN, and a parent of a child with CP and CCN. Megan has focused on an ethics submission, research activity design, and study recruitment. As part of Megan's work, she has submitted a high-risk ethics application to Deakin University.



Affiliated CP-Achieve Higher Degree Research Students

CP-Achieve has a number of affiliated Higher Degree Research students who are completing related work and supervised by CP-Achieve researchers.

John Carey (PhD)

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

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

Abby Thevarajah (PhD)

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

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

Loren Apokourastos (Masters)

Supervisors: Associate Professor Kimberley Docking, Dr Hans Bogaardt

Project Name: Dysphagia in young adults with cerebral palsy

Utsana Tonmakuyakul (PhD)

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

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

Jacinta Quartermaine (PhD)

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

Project Name: Participation experiences of young people with cerebral palsy

James Czencz (PhD)

Supervisors: Professor Peter Wilson, Professor

Christine Imms, Professor Nora Shields, Dr Margaret Wallen

Project Name: Evaluating exercise interventions to improve activity, participation and quality of life for those living with complex forms of cerebral palsy

Magnus Ivarsson (PhD)

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

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

Katie Headrick (PhD)

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

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

Kerry Britt (PhD)

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

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

Rowan Johnson (PhD)

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

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

YEAR IN REVIEW



Improving both physical and mental health

3 Surveys of young people developed and recruiting
2 Mental health tool kits
Developed major data linkage study to determine health service use



Building supportive environments

NHMRC MRFF application submitted
6 Projects underway at various stages of development, recruitment, analysis
6 PhD students, 8 honours students, 2 capstone students
2 Awards for FitSkills program



CP-Achieve reach

10 Webinars held
1258 Newsletter subscriptions (total)
2,448 Social media followers



Consumer involvement

3 Consumer advisory groups
2 Consumer groups under development
10 Individual consumers working with research teams
1 PhD and 2 consumers- consumer involvement evaluation
2 Honours students and 2 consumers-mentorship evaluation
State trustees grant awarded



CP- Achieve team

5 PhD students
4 Postdoctoral Research Fellows
10 CIs, 10 AIs and 23 Research Associates
10 Affiliated CP-Achieve HDR Students
3 Coordinators (Research, Consumer- Young People, Consumer- Families)



Publications and presentations

19 Presentations (national, international and online platforms)
14 Publications and articles published



CP-ACHIEVE RESEARCH PROGRAMS: PROGRESS



Improving both physical and mental health

- Data to be gathered via three surveys of young people – recruitment underway and data to be analysed.
- Two systematic reviews to understand the prevalence and nature of fatigue and mental health conditions in young people with CP.
- Two toolkits to help parents/carers and health professionals to recognise the signs and symptoms of mental health issues in young people with CP.
- PhD student researching conversations about sexuality for adolescents with CP and CCN.



Understanding health service use and outcomes

- Major data linkage study to determine use of a range of health services.



Adapting an evidence-based lifestyle program to Australian context

- Preliminary work commenced by honours/PhD student including finalising and registering review, and data extraction.
- Awaiting funding outcome for NHMRC MRFF application submitted by postdoctoral fellows.



Creating pathways from rehabilitation to recreation

- PhD student completed and published qualitative study of gym experiences for young adults with CP. Delphi study completed and manuscript drafted. Second qualitative study- social support implementation in community gyms underway.



Expanding available exercise evidence to those with complex disability

- Two PhD students working on this project.
- Evaluation of community based physical activity interventions complete, two systematic reviews completed, two qualitative studies in development.



Understanding the needs and perspectives of people with CP and their families

- PhD student conducted scoping review. Qualitative study underway.
- 16 young people with CP interviewed; currently undergoing data analysis.



Translating available participation-focused intervention evidence to the Australian context

- Two projects underway with data collection, analysis, and systematic review

WHAT ELSE ARE WE DOING?



Mindfulness in CP

- Randomised controlled trial for adults with anxiety and or emotional regulation difficulties.
- Four week intervention completed and qualitative study to commence.



Transition to independent living

- Adolescent and Young Adults with CP and Family Member Transition to Independent Living surveys developed. Consultations taking place with CP-Achieve Advisory Groups: Parent Advisory Group, CP Unite and CP Voice.
- Awaiting ethics application outcome from surveys before progressing to ethics for approval.



Transition and services for adults

- Team working on what is needed in this area. Program logic has been undertaken to define short, medium and long-term objectives to achieve goals of improving the health care of adults.



Consumer Involvement

- Evaluation of mentor program for young adult research partners. Interviewed young adults and mentors to identify perspectives on the mentor program to inform its future development.
- Evaluation of consumer involvement in CP-Achieve. Commenced a scoping review to identify evaluation tools and methods.

OUR OUTPUTS

Publications and articles

1. Bektashi, 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>

2. Dutia, I. M., Eres, R., Sawyer, S. M., Johnston, L., Reddihough, D., Cleary, S., & Coghill, D. (2021). Protocol for systematic review of measurement of fatigue in people with cerebral palsy. medRxiv, doi:10.1101/2021.07.20.21260898

3. Dutia, I.M., Tweedy, S.M. (2021). The Paralympics strive for inclusion. But some rules unfairly exclude athletes with severe disabilities. *The Conversation*. <https://theconversation.com/the-paralympics-strive-for-inclusion-but-some-rules-unfairly-exclude-athletes-with-severe-disabilities-166347>

4. Harvey, A., Waugh, M. C., Rice, J., Antolovich, G., Copeland, L., Orsini, F., Scheinberg, A., McKinnon, C., Thorley, M., Baker, F., Chalkiadis, G., & Stewart, K. (2021). A pilot feasibility study of gabapentin for managing pain in children with dystonic cerebral palsy. *BMC pediatrics*, 21(1), 368. <https://doi.org/10.1186/s12887-021-02847-1>

5. 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>

6. Headrick, K., Thornton, M., Hogan, A., Deramore Denver, B., Drake, G., & Wallen, M. (2022). Consumer involvement in research - parent perceptions of partnership in cerebral palsy research: a qualitative study. *Disability and Rehabilitation*, 45(3), 483–493. <https://doi.org/10.1080/09638288.2022.2034992>

7. Hickey, L., Kuyucak, O., Clausen, L. & Imms, C. (2022). Mapping the focus of research conducted with adults with cerebral palsy: An overview of systematic reviews. *Disability and Rehabilitation*, 45(2):185-208. doi: 10.1080/09638288.2022.2032412

8. Karlsson, P., Shepherd, M., Honan, I. (2022). Accommodations to cognitive assessment for a child with dyskinetic cerebral palsy: case study. *Disability and Rehabilitation: Assistive Technology*. doi: 10.1080/17483107.2022.2089244

9. Kerr, C., Novak, I., Shields, N., Ames, A., Best Service Best Time Author Group, & Imms, C. (2022). Do supports and barriers to routine clinical assessment for children with cerebral palsy change over time? A mixed methods study. *Disability and Rehabilitation*, 1–11. Advance online publication. <https://doi.org/10.1080/09638288.2022.2046874>

10. McKenzie, G., Shields, N., & Willis, C. (2022). 'Finding what works for me' - a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. *Disability and Rehabilitation*, 1–8. Advance online publication. <https://doi.org/10.1080/09638288.2022.2083243>

11. Orlandi, S., House, S. C., Karlsson, P., Saab, R., & Chau, T. (2021). Brain-Computer Interfaces for Children With Complex Communication Needs and Limited Mobility: A Systematic Review.

Frontiers in human neuroscience, 15, 643294. <https://doi.org/10.3389/fnhum.2021.643294>

12. Pennacchia, J. (2022). Planning research with people who use AAC: are we on the same page? *AGOSCI In Focus*, 51: 28-31.

13. Stewart, K., Lewis, J., Wallen, M., Bear, N., & Harvey, A. (2021). The Dyskinetic Cerebral Palsy Functional Impact Scale: development and validation of a new tool. *Developmental Medicine Child Neurology*, 63(12), 1469–1475.

<https://doi.org/10.1111/dmcn.14960>

14. Toovey, R. A. M., Harvey, A. R., McGinley, J. L., Lee, K. J., Shih, S. T. F., & Spittle, A. J. (2022). Task-specific training for bicycle-riding goals in ambulant children with cerebral palsy: a randomized controlled trial. *Developmental Medicine Child Neurology*, 64(2), 243–252.

<https://doi.org/10.1111/dmcn.15029>

Presentations and talks

1. Anaby, D., Imms, C., Dada, S., Piskur B., & Schakel, F. (2022). Let's LEAP together: Towards a participation-focused practice and a pediatric rehabilitation paradigm shift. *AusACPDM/IAACD 2022: Better Together*; 1-5 March 2022; virtual conference.

2. Cleary, S. (2022). A systematic review and meta-analysis of the effects of community-based physical activity programs for adolescents and young adults with disability. *AusACPDM/IAACD 2022: Better Together*; 1-5 March 2022; virtual conference.

3. Czencz, J. (2022). The effect of exercise interventions on participation and quality of life for adults with cerebral palsy - systematic review. *AusACPDM/IAACD 2022: Better Together*; 1-5 March 2022; virtual conference.



4. Ding, J. (2022). Preliminary findings from Study 1. Monash University Physiotherapy Seminar Series; 31 May 2022; virtual.
5. Dutia, I. M (2021). Conducting accessible research for people with complex needs. ACU School of Allied Health Research Network; 2 December 2021; Brisbane, Australia.
6. 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. AusACPDM/IAACD 2022: Better Together; 1-5 March 2022; virtual conference.
7. Karlsson, P., & McEwan, A. (2021). Emerging Technologies for Communication. In the Speech Pathology Discipline Research Symposium; July 2021; Sydney, Australia.
8. Karlsson, P. (2022). Research updates – Technologies. In the Therapy Conference; May 2022; Sydney, Australia.
9. Karlsson, P., Griffiths, T., Himmelmann, K., Clarke, M., Allsop, A., Monbaliu, E., Bekteshi, S., Pereksles, R., & Wallen, M. (2021). Clinical Guidelines for Eye-Gaze Control for People with Cerebral Palsy. Paper presented at the virtual Communication Matters conference; 13 - 17 September 2021; Leeds, United Kingdom.
10. McKenzie, G. (2021). 'Finding what works for me'—a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. CPISRA conference; December 2021; virtual.
11. McKenzie, G. (2021). Barriers and facilitators of physical activity participation for young people and adults with childhood-onset physical disability: a mixed methods systematic review. CPISRA conference; December 2021; virtual.

12. McKenzie, G. (2022). 'Finding what works for me'—a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. AusACPDM/IAACD 2022: Better Together; 1-5 March 2022; virtual conference.
13. Morgan, P. (2022). Professor Prue Morgan- Adults with Cerebral Palsy. Clinical teaching tips. 'A Neuro Physio Podcast'; 25 January 2022; online.
14. Morgan, P. (2022). Maximising lifespan mobility in adults with cerebral palsy. Australian Physiotherapy Association THRIVE conference; May 2022; webinar.
15. Morgan, P., & Reedman, S. (2022). Maximising physical activity participation opportunities and measuring physical participation outcomes. Adult and Aging SIG (offshoot of AACPD); April 2022; webinar.
16. O'Shea, A., & Walsh, M. (2021). Milkshakes and Cups of Tea: Talking About Consent with People with Intellectual Disability and Complex Communication Needs. Australasian Society for Intellectual Disability; November 2021; online conference.
17. Pennacchia, J. (2022). How do young people with complex communication needs tell us about their mental health? CP-ACHIEVE Webinar series; 30 May 2022; online.
18. Scheinberg, A., Imms, C., Knight, S., Toovey R., & Saloojee, G. (2022). Debate: Therapists are redundant: As we move to participation focused model of care, will evidence-based therapy be required? AusACPDM/IAACD 2022: Better Together; 1-5 March 2022; virtual conference.
19. Zhao, H., Karlsson, P., Kavehei, O., & McEwan, A. (2021) Reflections from Engineers, People with Cerebral Palsy and Caregivers. In IEEE SENSORS 2021 Conference; October 2021.



FINANCIAL STATEMENT

This Financial Statement is for the Income and Expenditure for the Financial Year ended 30 June 2022.

CP-Achieve was established in 2020 following the successful application to the NHMRC's Centres of Excellence funding scheme. Operationally, CP-Achieve is part of the Murdoch Children's Research Institute (MCRI) which is the Administering Institution. The program is run with the support and assistance of participating institutions including Deakin University, La Trobe University, Monash University, University of Melbourne, Australian Catholic University and the University of Sydney. MCRI and the participating institution(s) ensure the program is run at all times in accordance with the NHMRC Funding Agreement and the NHMRC Funding Policy.

MCRI is a non-for-profit organisation and provides resources towards the conduct of CP-Achieve. MCRI is responsible for the accounting function and all funds are paid to and administered by MCRI. The amounts in the financial statement are rounded off to the nearest thousand dollars unless otherwise indicated.

Income and expenditure	
Income	
NHMRC CRE Funding	\$353,000
Unspent funds carried forward	\$206,000
Total income	\$559,000
Expenses	
Staffing Expenses*	\$494,000
Non-Salary Expenses**	\$66,000
Total Expenses	\$560,000

* Staffing expenses are made up of the costs associated to run the operations and core research of the CRE. This includes MCRI salaries for administrative and research related positions, contractors, and PhD student stipends. Salaries include on costs and employee benefits.

** Non salary expenses refers to items required to carry out CRE work that are not covered by salary including but not limited to collaborations, conference scholarships, registries, translational materials, data linkage, and consumer involvement.

THANK YOU

We are grateful for the ongoing support of our research team, partnership organisations and for the professional relationships we have with our stakeholders including people with CP, their families and carers, clinical services, universities, support groups, volunteers and so many others who provide support and advice to our program.

We deeply appreciate the input that has been provided by our Stakeholder Advisory Group and other Advisory Groups. We thank them for their time, commitment and useful suggestions, and their ongoing support of CP-Achieve.

This program is funded by the National Health and Medical Research Council. We remain extremely grateful for this continued funding which allows us to continue our great work.



OUR PARTNERS

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

