Navigating consumer involvement in health and disability research

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

murdoch
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research
institute

CP-ACHIEVE
Centre of Research Excellence

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This resource is a compilation of interviews and discussions with CP-Achieve researchers, consumers and staff, developed in response to the need for real stories of implementing consumer involvement in health and disability research. The resource captures strategies, stories and key lessons of CP-Achieve's Consumer Involvement team during five years of operation from 2020 to 2025. A series of 13 short videos accompanies this resource.

Glossary

Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication, or AAC, describes the range of ways that a person communicates that does not involve speech. Augmentative communication involves using strategies to add to someone's speech. Alternative communication describes methods used instead of speech. Each AAC user employs unique combinations of AAC strategies to communicate.

Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM)

The Australasian Academy of Cerebral Palsy and Developmental Medicine (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.

Consumer

Adolescents and young adults with cerebral palsy, and the families and carers of young people with cerebral palsy, who collaborate with CP-Achieve.

Consumer coordinator

CP-Achieve staff members responsible for developing the Consumer Network and advisory groups, managing a small grants program for consumer involvement, orienting consumers and researchers to consumer involvement practice, matching consumers to research opportunities, and helping researchers plan for and implement good practice consumer involvement.

Consumer involvement

The process of involving consumers in opportunities to influence research that directly affects them.

Consumer Network

A network of 400 members that was established by CP-Achieve to engage consumers and the community with our work, inform them of research activities, and advertise opportunities for involvement.

CP-Achieve

The Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with Cerebral Palsy, a Centre of Research Excellence funded by the National Health and Medical Research Council.

CP

Cerebral palsy.

CP-Unite

A CP-Achieve advisory group of adults with cerebral palsy aged 18–30 years.

CP-Voice

A CP-Achieve advisory group of adolescents with cerebral palsy aged 10–18 years.

Consumer research partners

Individuals with lived experience of cerebral palsy involved in CP-Achieve's advisory groups or individual research projects.

One Group Our Voice

A CP-Achieve advisory group of adults with cerebral palsy who use AAC.

Parent Advisory Group

A CP-Achieve advisory group of parents and carers of young people with cerebral palsy.

Foreword

My passion for involving people with lived experience—consumers—in research was ignited years ago as I planned my PhD program. Conversations with parents of children with cerebral palsy helped me decide my research focus: to design and evaluate an intervention. Their generous feedback on my early ideas played a profound role in shaping its development and delivery.

Since then, I have worked to deepen my knowledge of consumer involvement in research and share what I have learnt. As the proud recipient of a Churchill Fellowship, I explored best practices in consumer involvement internationally, which greatly expanded my understanding of what is possible and how to implement meaningful involvement. I was also honoured to join CP-Achieve as the lead for consumer involvement.

CP-Achieve brought together a diverse range of experiences and perspectives. Seasoned researchers provided leadership and guidance to those newer to the consumer involvement journey. Less-experienced researchers enthusiastically embraced consumer involvement and inspired and supported each other. Our consumer research partners brought lived experience and insight, ensuring our work remained grounded, meaningful and impactful. Meanwhile, consumer coordinators acted as the bridge across all our voices, fostering connection and collaboration. Together, we formed a cohesive and dynamic community, united by a shared commitment to rigorous, meaningful and inclusive research. Knowledge Translation Fellow, Claire Rowland, has corralled our voices to capture our strengths and convey the challenges in our collaborative journey.

I don’t believe that consumer involvement always requires large-scale initiatives like those in CP-Achieve. Valuable insights also come from targeted conversations, like those that shaped my own PhD journey, or from smaller-scale initiatives. I do believe that any level of consumer involvement is better than none, provided it is done respectfully and with genuine intent. If we start with open, authentic dialogue and build from there, we can create research that is not only methodologically sound but also deeply connected to real-world experiences.

Regardless of your research background and expertise, I hope you will draw from and build on the stories and strategies we present in this resource. I challenge you to tell your own stories and share your own strategies, thereby contributing to ongoing discussion, education and advocacy for consumer involvement in research.

Margaret Wallen

Chief investigator and consumer involvement theme leader, CP-Achieve

Associate professor in occupational therapy, Australian Catholic University

Contents

Chapter 1

Welcome

> “Welcome to CP-Achieve’s consumer involvement journey, which began on the land of the Wurundjeri people of the Kulin Nation. I’m Professor Dinah Reddihough, Principal Investigator of the CP-Achieve program of research. In this section, I’ll provide an overview of CP-Achieve and this resource—its purpose, creation and intended audience. I’ll also guide you on how to use it to enhance your own consumer involvement practice.”

Professor Dinah Reddihough, Principal Investigator

Follow this link to hear Professor Dinah Reddihough (Principal Investigator) talk about CP-Achieve and why we are sharing our consumer involvement story.

What is CP-Achieve?

The Australian Centre for Health, Independence, Economic participation and Value Enhanced care for adolescents and young adults with Cerebral Palsy (CP-Achieve) was a Centre of Research Excellence (CRE) funded by the National Health and Medical Research Council of Australia. Running from 2020 to 2025, it aimed to develop research that would support people with cerebral palsy 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**. CP-Achieve involved 28 researchers, 10 PhD candidates and 4 postdoctoral scholars.[1]

Table 1 Summary of CP-Achieve research programs and themes

CP-Achieve's research program
CP-Achieve had two main research programs: • Improving the physical and mental health of adolescents and young adults with cerebral palsy. • Building supportive family, community and health service environments that help young people take part in life situations that are important to them.
Cross cutting themes
Cross-cutting themes of the program were: • Promoting the participation of people with cerebral palsy in daily life. • Health economics. • Developing a specialist workforce to support people with cerebral palsy. • Consumer involvement of people with cerebral palsy and parents of young people with cerebral palsy in research activities.

As a cross-cutting theme, consumer involvement was **promoted** by Chief Investigators and the Consumer Involvement Theme Leader and **resourced** through a two-person part-time Consumer Involvement team, a **mentor program** and a **small grants program**.

Some of the unique components of CP-Achieve's consumer involvement work were:

A **centre-wide approach** to consumer involvement – with shared learning on resourcing consumer involvement

A **Consumer Network** of over 400 people, including young people with cerebral palsy, families and carers

Four consumer **advisory groups** of different stakeholders: **adolescents, young adults, augmentative and alternative communication users**, and **parents** of young people with cerebral palsy

Consumers working as part of **individual research teams**

Committed researchers who developed or built on existing skills and experiences in consumer involvement in health and disability research, and **drove good practice** through mentoring, supervision or peer-to-peer sharing, or through in-service education and advice.

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[1] See full list of researchers, consumers and staff from CP-Achieve in 12. The CP-Achieve 'Family'.

What is this resource?

This resource is not peddling a particular theory of consumer involvement and does not have an exhaustive list of tools. Instead, it tells CP-Achieve's story of consumer involvement – the process of involving individuals with lived experience of cerebral palsy, and parents and carers of young people with cerebral palsy – in our research.

It covers everything from **planning and implementing** consumer involvement to **transitioning** consumers at the end of the program and the **support** provided to researchers across CP-Achieve to facilitate consumer involvement. Approaches for building **consumer wellbeing, community and sense of safety,** which were fundamental to our consumer involvement success, are also explored.

Why share CP-Achieve's stories of consumer involvement?

So much of learning about consumer involvement in research occurs through **informal and formal peer networks** and by **sharing real-life stories** about how consumer involvement happens.

By showcasing strategies and stories from our researchers, staff and consumers, we encourage the reader to open up and deepen peer-based and supervisory conversations about authentic consumer involvement. By sharing our strengths and the challenges we navigated, we hope to inspire curiosity and encourage new and improved practice in health and disability research. We focus on consumer involvement in all its forms and how even small steps can deliver big outcomes. We hope that readers draw from CP-Achieve's experience to drive new and creative real-world solutions befitting their context.

> **"Our supervisors frequently pass on our details to those interested in consumer involvement, and we enjoy helping guide them. This is a great opportunity to grow the practice, and we love sharing information."**
>
> **Jacinta Pennacchia, PhD Candidate**

How is the resource structured?

The document has been structured to guide the reader through key stages and resourcing of consumer involvement, with **learning opportunities** throughout.

Each section features different *consumer involvement champions* from CP-Achieve who guide you through their story of consumer involvement. Links to resources and videos further illuminate concepts and ideas. These stories are only a snapshot of the collective knowledge, skills and experiences of the CP-Achieve 'Family'.[2] Sections are linked where relevant, and comments and quotes from consumers and researchers are featured throughout.

The materials can be read in a linear fashion (and we would recommend this); however, the reader can also jump to the relevant topic as needed:

- **Section 2 to 4** focus on how CP-Achieve structured, resourced, funded and embedded consumer involvement in research practice.
- **Sections 5 to 10** present examples of consumer involvement in CP-Achieve research, each highlighting a different topic relevant to the practical application of consumer involvement.
- **Sections 11 to 13** contain the steps to get started and lists of tools, resources and an index for finding specific information.

Who is this resource for?

This resource can be used widely in several ways, including by:

- CP-Achieve researchers and consumers wanting to celebrate their consumer involvement practice, access working examples of forms for future use, and share resources in peer networks
- research centres establishing consumer involvement units, particularly with young people with disabilities and their families and carers
- individual researchers seeking practical insights into involving consumers - young people, and families and carers - in health and disability research.

Opportunities for reflection and learning

Look for the following symbols throughout the document to support your reflection and learning:

Reflection point

When you see a reflection point, take a moment to reflect on key ideas in the resources in your own context and identify what you can take with you from this story to build and improve your own practice.

Key learning

Key learnings of CP-Achieve about consumer involvement are highlighted with this symbol.

Good practice

This symbol is used for examples that we think show good practice.

Key takeaways

This symbol is used to summarise the key takeaways for each section of the document.

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[2] The full list of CP-Achieve staff, researchers and consumers can be found in 12. The CP-Achieve 'Family'.

Chapter 2

Consumer involvement in CP-Achieve

> “In CP-Achieve, people with cerebral palsy and families and carers with young people who have cerebral palsy influenced research that directly affects them. We followed the principle of ‘nothing about us, without us’.
>
> In this section, I’ll explain:
>
> - the term ‘consumers’ and ‘consumer research partner’
> - CP-Achieve’s Consumer Network and advisory groups
> - our wish to achieve diversity of consumer experience
> - benefits and challenges of consumer involvement.”

Associate Professor Margaret Wallen, Chief Investigator and Consumer Involvement Theme Leader

Follow this link

To hear Associate Professor Margaret Wallen talk about CP-Achieve’s advisory groups and consumer research partners.

Who are CP-Achieve's consumers?

CP-Achieve uses the term 'consumer' to refer to adolescents and young adults with cerebral palsy and the families and carers of young people with cerebral palsy who collaborated with us. This term was chosen based on **feedback** from consumers working with us, who viewed 'consumers' as **empowering**. It also aligns with terminology used by key organisations, including CP-Achieve's funder, the National Health and Medical Research Council.

Reflection point

Does the term 'consumer' resonate with people with lived experience who are involved in your research?

Consumer Research Partners

CP-Achieve strongly believes that consumer **priorities and needs** should drive research, that consumers are **experts** about their own lives, that their involvement will lead to better quality research outcomes, and make findings more **rigorous, meaningful and relevant**.

Consumers contributed to CP-Achieve as consumer research partners[3] on advisory groups or individual research projects and played an active role in research across any or all aspects of the research cycle, as shown in Figure 1.

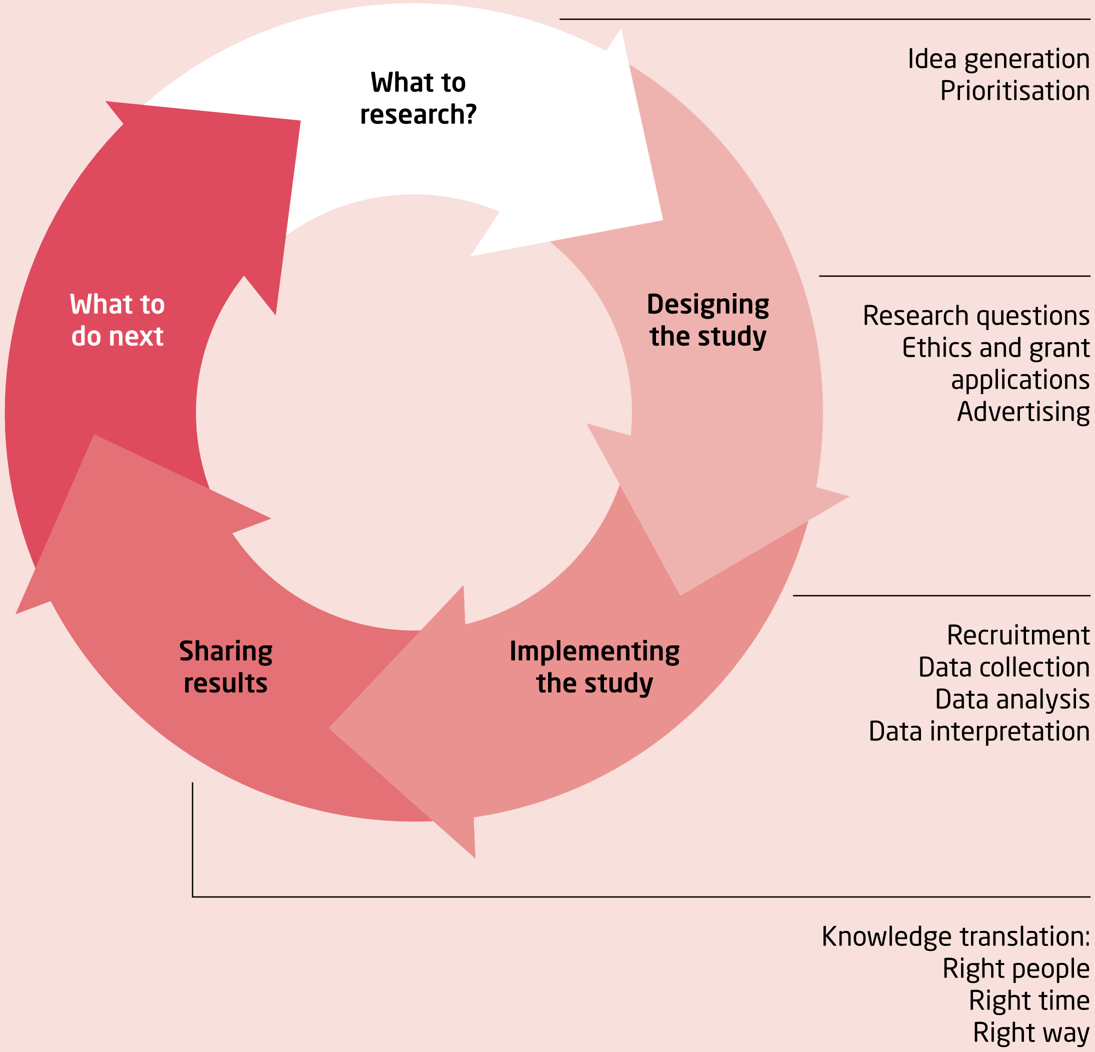

Figure 1 Consumer research partners' involvement across the research cycle

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[3] A complete list of consumer research partners can be found in [12. The CP-Achieve Family.](#)

Reasons consumers got involved in CP-Achieve research

Consumers chose to be involved in CP-Achieve research for many reasons - such as employment, to extend their social network, to gain new professional skills, and to advocate for services that meet their needs. Kylie, Gaurav and Michelle highlight some of these reasons.

Understanding **individual reasons** for involvement and approaching consumers with **understanding and empathy** is critical to enabling a positive consumer involvement experience and maximising the opportunity of working with consumers.

Reflection point

How will you identify your consumers' motivations for becoming involved in research?

Follow this link

To listen to Consumer Coordinators Sevastine Katsakis and Carolyn Pinto and Consumer Research Partner, Freya Munzel talk about consumer motivations to join CP-Achieve.

Gaurav Thakkar, Consumer Research Partner, young adult with cerebral palsy

> "I wanted to try something different. I ended up meeting other people with cerebral palsy and learnt from their experiences. Before that, I had never met anyone with cerebral palsy that faced similar issues to me."

> "I worked in the CP-Achieve Parent Advisory Group and on specific projects. I became involved because of the harms that my son and myself experienced during our medical journey. The more people that I speak to, the more I realise that my son's story is not isolated. Being involved in research and getting people to understand the perspectives of the families and of the young people with cerebral palsy is very important to me."

Kylie Brown, Consumer Research Partner, parent

> "I got a little bit frustrated with some of the research that was being done in the sector. We were researching things that seemed obvious and I was left asking when we could research something that would actually make a difference. That is why I got involved in CP-Achieve - to support better research and stay on top of the latest findings."

Michelle Roger, Consumer Research Partner, parent

CP-Achieve's Consumer Network

CP-Achieve established a Consumer Network of adolescents and young adults with cerebral palsy and of families and carers to:

- **engage** consumers and the community with our work
- **inform** them of research activities
- **advertise** opportunities for involvement.

To create the Network, consumer coordinators contacted over 90 support services and advocacy groups for people with cerebral palsy and other co-occurring conditions, such as autism and epilepsy. These organisations promoted opportunities to join CP-Achieve's Consumer Network through their own networks. As a result, it grew to 400 members within six months. CP-Achieve's consumer coordinators managed the Network with regular communication through email, bulletins and social media, to strengthen relationships, promote a sense of community, and ensure a safe, supportive involvement process.

Reflection point

What organisations could you approach to develop a network of consumers for your program?

CP-Achieve's Advisory Groups

Three of CP-Achieve's four advisory groups of consumers were established early in the project to ensure researchers had access to consumer guidance to **inform the initial stages of their research** while securing funding for ongoing and more extensive involvement. These three groups were CP-Voice, CP-Unite and CP-Achieve's Parent Advisory Group. A fourth advisory group, One Group Our Voice, was established mid-project to address a gap in the involvement of consumers who used augmentative and alternative communication (AAC) in CP-Achieve research. The four advisory groups are described in Table 2.

Table 2 CP-Achieve's advisory groups

Advisory Group	Description
CP-Voice	Adolescents with cerebral palsy aged 10–18 years.
CP-Unite	Young adults with cerebral palsy aged 18–30 years.
Parent Advisory Group (PAG)	Parents and carers of young people with cerebral palsy.
One Group Our Voice	Young adults with cerebral palsy who use AAC.

Opportunities to join the advisory groups were advertised through the Consumer Network, social media and aligned organisations. As members of advisory groups, consumer research partners provided **targeted feedback** on specific aspects of a project.

CP-Unite was the first advisory group of CP-Achieve, with seven members. They were pivotal in setting the direction of CP-Achieve's cross-cutting Participation Theme and provided advice on many projects throughout the life of CP-Achieve.

Figure 2 CP-Unite members Nicole, Alana, Greg, Rohan, Gaurav, Cassandra and Alesia

CP-Voice is featured in 6. Building community and a sense of safety for consumers **and One Group Our Voice is featured in** 9. Working with young adults who use augmentative and alternative communication.

The Parent Advisory Group was the largest group in CP-Achieve. With 13 active members, the Parent Advisory Group had a substantial impact across research themes and projects. The members were mostly parents of young people who found it difficult to advocate for themselves directly.

Figure 3 Parent Advisory Group members Janine, Kylie, Michelle, Bianca, Wendy, Ebony, Helen, Toni, Michelle, Chris, Joan, Helen, and Julie.

Individual research partners working on CP-Achieve projects

Individual research partners were more **deeply engaged** in an ongoing way than advisory groups on CP-Achieve's research projects, contributing to discussions, decision making and research activities across multiple stages of the research cycle.

Research teams frequently involved advisory groups and individual consumer research partners. 7. Involving consumers across the research cycle provides an example.

Reflection point

What opportunities exist to involve advisory groups and/or individual consumer research partners in your research?

Many consumer research partners joined the Consumer Network, then an advisory group and/or specific research projects. Several used the experience of working with CP-Achieve to take up other opportunities. Rohan is an example. Starting as a member of CP-Unite, he then joined Project TEAM as a consumer research partner and went on to be awarded a Churchill Fellowship, as described in the story overleaf.

> **“For individual research projects, we recommended a minimum of two consumer research partners per project to provide peer support and help reduce power imbalances between researchers and consumers.”**

Carolyn Pinto, Consumer Coordinator

Rohan's story: Churchill Fellow and consumer advisor

'I became a consumer research partner with CP-Achieve because I wanted to influence community access and service provision for people with disabilities. Advocating for more consumer involvement in the (disability) sector is really important to me as well.

One of the CP-Achieve projects I have worked on is Project TEAM (Teens Making Environment and Activity Modifications project). Project TEAM is an intervention that teaches individuals with disabilities how to identify the barriers to their participation in the community and generate solutions to resolve them. The Australia Working Group, which includes CP-Achieve in Australia and Project TEAM in America, is exploring how this intervention can be adapted and implemented for use in Australia. To support this aim, I applied for and was awarded a Churchill Fellowship.

I travelled to Florida and Boston, interviewing young people involved in the original Project TEAM trial. I also got to practise some of the project team activities from the original program with a group of young people. It was really cool just to immerse myself in the experience, explore the history of Project TEAM and the disability movement in America more generally, and provide recommendations for the Australian project.

Now that I've been involved in lived experience research for several years, I know exactly what I'd like to do career-wise. I'd like to be in the research industry, long term. It's been great to work with like-minded individuals, like my CP-Achieve mentor and research team who are experienced in research and who can provide me with the skill set to do it well.'

Read Rohan's Churchill Fellowship report here

Consumer diversity

CP-Achieve embraced a **people-first approach**, focusing on individuals rather than defining them by their disability. Consumers collaborating with CP-Achieve were not asked to provide details about their diagnosis, disability level or other characteristics. Similarly, parents and caregivers were not required to share their child's diagnosis or cerebral palsy characteristics, though many did so voluntarily. Consumer coordinators discussed necessary support with each consumer to ensure accessible research opportunities.

We aimed to involve consumers with **diverse perspectives**, welcoming young people with all presentations of cerebral palsy, from various backgrounds and locations across Australia. Accessibility was a priority, and there was broad representation across genders and states in CP-Voice and CP-Unite.

We took measures to address potential **gaps** in consumer experiences. After identifying a gap in the involvement of consumers who used AAC, for example, we established the fourth advisory group, One Group Our Voice. We also developed a diversity strategy[4] for the Parent Advisory Group, and reached out to numerous groups for advice on inviting consumer involvement of people across socioeconomic, LGBTQIA+ and cultural groups and ways to seek these perspectives in the absence of representation from these groups.

We recognise that we did not achieve sufficient perspectives of fathers, non-parent carers, First Nations peoples, people from culturally and linguistically diverse backgrounds, or members of the LGBTQIA+ community.

Key learning

Promoting consumer diversity requires **targeted strategies and approaches**. We strongly recommend developing and implementing a diversity strategy early in the life of research. This will require a dedicated early effort in building relationships with organisations that represent diverse populations, such as First Nations and culturally and linguistically diverse disability groups. Without an existing, trusting relationship, organisations may not feel comfortable facilitating contact with their members to identify consumers for research.

Reflection point

For the advisory groups you're involved in, whose perspectives are well represented? Whose are **missing**?

What networks and advice can you **access** to promote greater diversity among your consumer network?

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[4] The diversity strategy is available for download in 11. Getting started: Steps for your journey

> “If you want your research to impact the disability community and improve their lives, prioritise consumer involvement! Try to include multiple perspectives so that you can gain varied perspectives. Communicate what you seek in a partner and emphasise their significance to your work. This will not just boost their self-worth but will also give them the ability to make a difference in the world.”

Gaurav Thakkar, Consumer Research Partner, young adult with cerebral palsy

Benefits of involving consumers in health and disability research

CP-Achieve PhD Candidate, Jackie Ding, explains that involving consumers increases the likelihood that research outcomes are relevant and useful:

> “One of the biggest benefits is peace of mind, knowing that the work that we have been doing is going to be fit for purpose. I think involving everyone and having a collaborative process generates different ideas that I might not have thought of. Everyone is working together, and that means the result is much more likely to be appropriate.”

Other benefits shared by CP-Achieve researchers for involving consumers in their research range from expanding their research scope and refining approaches to be more **aligned with consumer needs**, having their work increasingly recognised and valued by other researchers, receiving positive feedback and encouragement from consumers, and **developing new ideas and partnerships** for future research.

Consumers frequently reported **benefits** from their involvement as consumers in research, such as meeting others with similar experiences, gaining new skills and employment, better understanding of self-advocacy and its implementation, new career pathways and contributing to research that makes a difference. Many young people also gained insight into the diversity of cerebral palsy and a deeper appreciation of others' lived experiences, recognising the similarities and differences compared to their own. Young people highlighted the importance of the advisory groups for connection, community and purpose.

For Michelle Roger, a parent of a young person with cerebral palsy, working as a consumer research partner was empowering and expanded her scope of influence:

> “The main benefit has been gaining a sense of empowerment. I feel like someone actually values what I have to say. I feel that I am contributing to something larger than just my own family and keeping my brain active whilst supporting my daughter at home.”

Reflection point

What benefits do you **expect** from involving consumers in your research, and what may be the **benefits for consumers**?

How can you capture these benefits throughout your project and share them?

Challenges of involving consumers in CP-Achieve research

Young people involved in CP-Achieve's advisory groups sought more regular and face-to-face meetings to **optimise continuity** between meetings and their ability to **share their views**. Some reported challenges managing the Zoom environment, especially with balancing a wish to be heard without interrupting others.

Parent Advisory Group members expressed a desire to have **higher levels of influence** on projects and to be represented in forums such as conferences while feeling **time-poor** as they managed multiple demands on their time.

Consumers with **intellectual disability** were involved in advisory groups alongside those without intellectual disabilities. While the process was paced to support the communication and processing needs of a range of participants, we recognise that the needs of consumers with intellectual disabilities were not always fully addressed and required additional consideration.

Consumer involvement is not effortless for researchers, young people or families. It **takes time, commitment, resources**, and for researchers, the requirement to develop **knowledge and skills**. Young people with cerebral palsy and their families have other lives, often complicated by higher support needs, conflicting priorities, risk of fatigue and higher administrative burdens associated with managing medical, allied health and other appointments, and funding supports such as the National Disability Insurance Scheme.

A major concern for consumers was the **ultimate destination of the research findings and publications** and their impact on the future. They wanted their voices and the research to make an **impact**. Demonstrating impact over the short term was challenging.

Reflection point

What specific challenges may your consumers experience during their involvement in your research?

What actions could you take now to minimise potential challenges and maximise involvement?

Key takeaways

Consumer involvement is pivotal to designing, implementing and translating research that optimises outcomes for the consumers' community.

Consumers can be involved in many ways in research, including in advisory groups and as individual consumer research partners on projects. Both approaches have benefits for researchers and consumers.

Develop a diversity strategy to overtly invite and involve consumers with diverse backgrounds and perspectives.

Challenges exist. Anticipate challenges and proactively plan to address them.

Chapter 3

Embedding consumer involvement across CP-Achieve

> “Increasingly, researchers are expected to involve consumers in health and disability research but may need practical experience in how to make this happen, particularly at scale. In this section, we will explore:
>
> - the ways in which consumer involvement was embedded across CP-Achieve
> - the Consumer Involvement team’s structure and function
> - successes and challenges of embedding consumer involvement across CP-Achieve
> - transitioning consumers at the end of CP-Achieve.”

Sevastine Katsakis, Consumer Coordinator

Carolyn Pinto, Consumer Coordinator

Follow this link

To hear Associate Professor Margaret Wallen talk about the ways in which CP-Achieve embedded consumer involvement across the Centre.

Authentic consumer involvement as a CP-Achieve priority

Carolyn

I began working as a consumer coordinator in 2022, bringing my **lived experience** as a parent of a young person with disability to support parents' involvement in the research. Professionally, having worked in government policy roles, I had experienced the value of involving people with lived experience in informing policy and program development. Joining CP-Achieve mid-program, I was impressed by how deeply consumer involvement was integrated. **Consumer rights**, their **lived experience expertise** and ability to drive more **rigorous, meaningful and quality research** were core beliefs of the program founders. Consumer involvement was embedded in CP-Achieve's design, and supported by a **strong leadership team**, a Consumer Involvement Theme Leader, and two part-time **consumer coordinators** (including me). The key elements facilitating consumer involvement in CP-Achieve are outlined in Table 3.

Table 3 Factors facilitating consumer involvement in CP-Achieve

Core beliefs	Program leadership		Practical support for researchers and consumers	
Consumers have a fundamental right to be included in research that is about them Consumers are experts in their own lives Consumer involvement will drive more rigorous, meaningful, and quality research	Consumer involvement was a cross-cutting theme of the research program, outlined in our grant agreement with NHMRC[5]	Chief investigators were experienced, committed to modelling consumer involvement approaches, and mentoring junior researchers	CP-Achieve ran a small grants program for consumer involvement[6]	CP-Achieve facilitated a conduit between researchers and consumers through CP-Achieve's Consumer Network and advisory groups[7]
	A Consumer Involvement Theme Leader was appointed to undertake targeted research, provide guidance to the consumer coordinators and mentor researchers	A Consumer Involvement team was established	Orientation, planning, budgeting and management support were provided to researchers[8]	A mentor program was established to support young consumers to engage with research processes and build confidence in sharing their ideas and perspectives
			Regular check-ins and community-building activities supported consumer mental health and sense of safety[9]	

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[5] National Health and Medical Research Council.

[6] Information about this program is available in 4. Funding for Consumer Involvement.

[7] The Consumer Network and advisory groups are explained in 2. Consumer Involvement in CP-Achieve.

[8] This is explored further in 5. Support to researchers to authentically involve consumers.

[9] These approaches are discussed in 6. Building community and a sense of safety for consumers.

> “From the very beginning, my supervisors made it quite clear how important it was to involve consumers.”

Jackie Ding,
PhD Candidate

> “It’s so funny when we talk to other research teams who haven’t touched consumer involvement and wouldn’t even think of touching it. We’re in a bubble of consumer involvement in CP-Achieve.”

James Czencz,
PhD Candidate

> “CP-Achieve’s processes and resources truly provide a benchmark for other researchers who are serious about involving consumers as research partners. Assigning consumer research leads experienced in consumer involvement has been critical to the success of CP-Achieve.”

CP-Achieve researcher

Reflection point

Do the leaders in your research program **signal the importance** of consumer involvement to researchers? How can this be fostered or strengthened?

How can you promote a consumer involvement **culture** in your research program?

Consumer involvement principles

For the consumer involvement team, **authentic consumer involvement** meant:

- honest and transparent collaboration where communication is key
- practices that promote a sense of psychological safety
- dedicated resources to develop and sustain consumer involvement, including individuals to support consumers and researchers
- paying consumers and acknowledging all their contributions.

These key concepts are captured in consumer involvement principles that drove our practice (summarised in Table 4).

Table 4 Principles and practices of consumer involvement in CP-Achieve

Overarching principle	**Authentic consumer involvement:** Research is conducted with, not to or about, individuals with cerebral palsy. This ensures respect for their rights and active participation in decision-making processes.
Involving consumer research partners	**Diversity:** Consumer research partners reflect experiences across a range of backgrounds, including those with diverse communication and intellectual abilities. **Wellbeing and sense of safety are paramount:** Consumers should feel respected and heard. Regular communication with consumers is essential to ensuring their wellbeing and safety. **Collaborative approach:** Involvement relies on open communication, building trusting, respectful relationships, and valuing diverse perspectives and experiences. **Acknowledgement and payment:** Consumers' contributions are acknowledged and fairly compensated.
Approaches for researchers	**Early and ongoing involvement:** Consumers are involved from the start and throughout all research stages, ensuring their input is integral to the process. **Flexibility in involvement:** A range of diverse and adaptable consumer involvement options are implemented to cater to varying consumer and researcher needs and resources, from information sharing to active co-investigation. Project meeting schedules should be able to accommodate consumers with work, caring and other commitments. **Support:** Support and resources are available to consumers to optimise their confidence and safety in their roles, including mentorship and emotional support, especially when addressing sensitive topics. **Closing the loop:** Consumers have the right to be advised of how they influenced research outcomes that they are involved in. **Monitoring and evaluation:** Consumer involvement activities are reported using standardised frameworks, such as GRIPP-2[10], and evaluated for effectiveness and impact to drive continuous improvement.
Practices	**Inclusivity and accessibility:** Consumer involvement materials are accessible to optimise the involvement of people from a range of backgrounds and abilities, including those with diverse communication and intellectual abilities. **Preparation:** Orientation is tailored for consumers and researchers to ensure effective collaboration. **Planning:** Researchers are supported to plan consumer involvement and set clear expectations with consumers around their roles, time commitments, project duration and level of influence. **Securing funding:** Provision of dedicated funding to support consumer involvement, including personnel to coordinate involvement, payment for consumer time and expertise, covering expenses associated with involvement and necessary resources.

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[10] Guidance for Reporting Involvement of Patients and the Public. See Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. BMJ, 358, j3453. https://doi.org/10.1136/bmj.j3453

The Consumer Involvement team

Sevastine

The **Consumer Involvement team** comprised three members: the Consumer Involvement Theme Leader, Associate Professor Margaret Wallen, and two consumer coordinators (including me). Debora Markelis, the Research Coordinator, also provided significant support, managing gift voucher payments to consumers on behalf of researchers and the consumer involvement small grants program budget. Our Principal Investigator, Professor Dinah Reddihough, lent strong support to the team and was an advocate for consumer involvement across the program.

Our **Consumer Involvement Theme Leader,** Associate Professor Margaret Wallen, oversaw the program's approach to consumer involvement, mentored researchers, provided advice, promoted sharing of information on consumer involvement in health and disability, and supported the consumer coordinators.

In collaboration with Margaret, Carolyn (and Joan before her) and I,[11] as part-time consumer coordinators, developed the Consumer Network and advisory groups, managed a small grants program for consumer involvement, oriented both consumers and researchers to consumer involvement practice, matched consumers to research opportunities, and helped researchers plan for and implement good practice consumer involvement. All consumer coordinators had lived experience; I have cerebral palsy and Carolyn (and Joan before her) are parents of young people with disability.

Our key tasks are captured in our job descriptions[12] and outlined in Table 5.

Table 5 Key tasks of the consumer coordinators

Tasks supporting consumer identification, community building, safety and wellbeing	Tasks building researcher capacity to involve consumers in research
• Develop a Consumer Network • Providing an orientation to CP-Achieve – its objectives and research program. This orientation included a Welcome Pack[13] exploring consumer roles and opportunities • Develop, coordinate and facilitate consumer advisory groups • Build relationships with individual consumers, getting to know their personal and research interests and goals • Develop consumer profiles capturing their interests and goals, and specific support needs. These profiles were shared with researchers to support knowledge about consumers prior to advisory group meetings or to support consumer onboarding to specific research projects • Matching consumers to research opportunities aligned to their interests and availability • Matching young consumers to mentors • Regular check-ins and troubleshooting support where required • Transition consumers at the end of research activities (for example, to other consumer involvement opportunities) and at the end of CP-Achieve	• Provision of an informal orientation to consumer involvement • Planning support for researchers requesting funding and/or support to identify consumers • Matching consumers to research opportunities • Briefing on specific considerations of working with selected consumers • Coordination and facilitation of advisory group meetings as needed • Trouble shooting support with consumer involvement • Encouraging researchers to attend relevant external education opportunities on consumer involvement and mental health first aid[14]

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[11] Joan Gains worked as a consumer coordinator at the outset of the Program. Carolyn took on the role in 2022.

[12] To access this document, go to 11. Getting started: Steps for your journey

[13] Ibid

[14] See https://www.mhfa.com.au/ for more details.

As you can see from Table 5 on the previous page, our work required **lived experience, empathy, community building, commitment to psychological safety, a deep knowledge of the consumers**, and a focus on creating **effective matches** between consumers and researchers. Consumer coordinators and researchers also needed skills to provide **wellbeing support** to consumers.

Reflection point

What consumer involvement support and resources can you access through your organisation?

What opportunities exist to ensure that people with lived experience are involved in consumer coordination roles?

Understanding consumers: A consumer coordinator priority

Understanding individual consumer experience, interests and involvement priorities was a core part of the consumer coordinator role. It was also critical to effectively matching consumers to research projects and to ensuring that consumers were adequately supported. **Lived experience** of cerebral palsy contributed to the consumer coordinators' understanding of **realities** faced by young people with disability and their families that can impact on their availability and involvement in research activities, such as:

- managing complex health needs and accessing services
- time poverty and administrative overload from therapy, medical appointments and disability support alongside daily family life
- fatigue, pain management and medical trauma from negative healthcare experiences
- future-related concerns.

By acknowledging these realities, consumer coordinators and researchers can help set boundaries, foster **supportive connections**, **match** consumers with researchers effectively, and **reduce barriers** to involvement. **Flexible options** and regular **check-ins** ensure both consumers and research projects are well supported.

For many consumers, particularly young consumers, holding an individual research partner or advisor role offers multiple benefits – social **connection, purpose, personal and professional identity** and **financial earnings**. Relationships between researchers and consumers may continue in future projects or evolve into friendships.

We prioritised managing the transition at the end of CP-Achieve to support consumers' health and wellbeing, recognising that some may experience a period of grieving for the loss of identity and connection that came through their consumer involvement.

Over the five-year program, only four out of more than 40 consumers – many with ongoing health conditions or complex communication needs – decided to step down from either the consumer advisory groups or individual research partnerships. This small attrition rate over the extended period is an achievement worth celebrating!

Key consumer involvement successes in CP-Achieve

Sevastine

Our key success was in establishing a program during COVID-19, which presented challenges like building a consumer network **online** instead of face-to-face. We retained almost all of our consumer research partners over the five years. This success was built on **strong consumer involvement structures and systems**, and the **support** provided to researchers and consumers throughout the program. We also valued and acknowledged the work of consumer research partners and ensured we supported opportunities like presenting at symposia and other meetings.

Carolyn

We saw a great uptake of consumer involvement across CP-Achieve. Researchers' consumer involvement skills and knowledge grew over the five years of CP-Achieve's operation. A survey in 2024 indicated that 21% of researchers felt **confident** in their skills and knowledge of consumer involvement prior to the program, relative to 84% of researchers in the final year. We also saw a shift towards **higher levels of consumer influence** in researchers' projects relative to prior experience. Although we aimed high in CP-Achieve, we also strongly believed that it is important to take the first step, do what can be done with the resources available, learn from the experience and iteratively improve as you go.

We are proud to share examples of journal publications completed with consumer involvement in Table 6.

Table 6 Research describing consumer involvement

Title and description	Involved consumers	Consumer partner listed as co-author	About consumer involvement
Perspectives of children and adolescents with cerebral palsy about involvement as research partners: A qualitative study. Asked young people with cerebral palsy why and how they would like to be involved as consumer research partners	✓	✓	✓
Consumer involvement in research - parent perceptions of partnership in cerebral palsy research: A qualitative study. Asked parents of young people with cerebral palsy how and why they would like to be involved as consumer research partners	✓	✓	✓
Experiences, opportunities and reflections from a collaborative research team of people with lived experience of cerebral palsy and health care professionals. Describes CP-Achieve's strategy for consumer involvement and provides an example	✓	✓	✓
Including people who use augmentative and alternative communication in qualitative research: Can you hear us? Presents a framework and guidance for involving AAC users in research as consumer research partners and participants	✓	✓	✓
A stakeholder-involved adaptation of pathways and resources for engagement and participation (PREP) material with young adults with complex disability in Australia: an implementation feasibility study. Involved two people with cerebral palsy as co-investigators and collaborated with an advisory group	✓	✓	
Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: An e-Delphi study. Involved two people with cerebral palsy in the design and implementation of this study	✓	✓	
Experiences of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. Involved three people with cerebral palsy to design and complete this scoping review	✓	✓	

Challenges faced in embedding consumer involvement across CP-Achieve

Sevastine

Embedding consumer involvement was not without challenges. We learnt to expect challenges, and being prepared assisted us in building adaptable approaches and practices.

Delays

Grant and ethics approvals often **took longer** than expected. When consumers were involved in developing these applications, it was important to communicate regularly and manage their **expectations about timelines**.

These delays could often impact CP-Achieve's small grants for consumer involvement. As these grants were allocated annually, they were often **underspent** due to project implementation delays, affecting the effective allocation and management of funds. Fund management was also impacted by challenges in adequately budgeting for potential accessibility needs that might not be needed (e.g. predicting the need to cover support worker costs).

Communication

Even after approvals or grants were obtained, delays in administering grants and recruiting participants were common. Unexplained **communication gaps with consumers occurred**, and we received enquiries from consumer research partners about delays in project activities after being onboarded, unsure when they would begin. Consumer coordinators bridged communication gaps and maintained relationships with consumers during times of infrequent communication from researchers.

Level of influence

In a few cases, we saw tension between consumers' desire for **more and earlier influence** on research design and implementation, and funding and practical realities placing limits on their involvement. Kylie Brown (consumer research partner, parent) commented:

> “**It felt too late in the process for us to have any foundational impact [on the research design]...it was a "the horse has already bolted" kind of situation.**”

In this context, the involvement opportunity occurred mid-project, after the project purpose and direction were established, and Kylie did not feel that the project direction aligned with the priorities she had identified as a parent of a child with cerebral palsy. Involving consumers at the beginning of the research cycle ensures that research targets the priorities and outcomes of the end user. In cases where consumers cannot be involved in deciding what to research (due to funding limitations, for example), **setting clear expectations** for consumer influence at the project outset can help offset disappointment and feelings of tokenistic involvement by consumers.

> “**If consumers are onboarded prior to grant or ethics approval, it is really important that consumers are aware of expected timeframes and advised of delays.**”

Carolyn Pinto,
Consumer Coordinator

Pictured below:
(L-R top) John Carey, Professor Prue Morgan, Dr Stacey Cleary, Dr Carlee Holmes

(L-R bottom) James Czencz, James Plummer

Pictured right: Professor David Coghill and Consumer Coordinator Sevastine Katsakis presenting mental health of young people with cerebral palsy.

Planning and organisation

Researchers involved in the development of this resource all spoke to the importance of being **well organised** to facilitate authentic consumer involvement. Many researchers underestimated the time needed to be adequately prepared for consumer involvement, for example, the time needed for sharing information with consumers well before meetings, coordinating meeting schedules, writing accessible agendas and minutes, following up after meetings, and managing timely payments to consumers in addition to undertaking the research itself. Time for planning and organisation (reflected in many stories in this resource) needs to be budgeted for and scheduled to work effectively.

Authorship

Authorship teams with consumers as co-authors of journal articles or co-presenters sometimes faced challenges when journals or conferences required all authors to declare an **organisational affiliation**.

Researcher confidence

Consumer involvement is a learning journey. CP-Achieve has strengthened researcher capacity and confidence in working with consumers, and now researchers are taking this forward and further developing their skills. A CP-Achieve researcher said:

> **“To me, consumer involvement is important but hard to do well. I feel my understanding has improved over the course of CP-Achieve. The coordinators and mentors had a huge part to play. However, there are still many aspects I am unsure of, and I think there is a lot of work to do.”**

Transitioning consumers at the end of CP-Achieve

Carolyn

The end of CP-Achieve heralded a **significant change** for many consumer research partners who had dedicated their time and expertise, developed relationships with researchers and other consumer research partners, and had strong emotional connections with the work they did. CP-Achieve was committed to supporting consumers to effectively transition out of CP-Achieve and plan future goals.

We set up a working group involving the consumer involvement team and consumers to develop and implement a **transition process** guided by The Bridges Transition Model[15]. Two fourth-year occupational therapy students conducted a literature review to identify unique transition issues experienced by young people with cerebral palsy to underpin our work. Professor Dinah Reddihough prepared a video announcing the program closure, thanking consumer research partners and inviting their involvement in transition activities. Online meetings were held with young people and parent advisors to discuss their **hopes, fears and concerns** about the transition, as well as opportunities to ease the process and plan for future advocacy and consumer involvement.

All consumer research partners expressed a strong desire to **maintain the connections** they formed through CP-Achieve and to continue serving as lived experience experts in research. They strongly communicated their wish for the research they undertook to be implemented, **drive change** and inform new practices. They also advocated for future research opportunities to uphold the same accessibility standards established by CP-Achieve.

Apart from actively and respectfully hearing and acknowledging consumer research partners' views on transition, our engagement led to outputs that consumers identified were meaningful to them as they finished their roles with CP-Achieve. We assured them that the **communication networks** that had been established would remain in place for them to continue to engage with each other. We wrote a **personalised letter** to each consumer including quotes from researchers about their unique contributions to their research. These letters also included a summary of and links to any publications and presentations they had contributed to. Finally, we provided a list of consumer **research partner opportunities** in other groups and organisations, with descriptions and links to websites, for consumer research partners to explore.

Reflection point

When do you need to start considering the transition needs of consumers and develop approaches to addressing these?

Key takeaways

High-level leadership, rights-based beliefs and practical support to consumers and researchers can create a strong consumer involvement culture.

Critical experience and skills for supporting consumer involvement include lived experience, empathy, community building, commitment to psychological safety, a deep knowledge of the consumers, and wellbeing support.

Authentic consumer involvement means:

- honest and transparent collaboration where communication is key
- practices that promote a sense of psychological safety
- dedicated resources to develop and sustain consumer involvement, including individuals to support consumers and researchers
- paying consumers and acknowledging all their contributions.

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[15] Bridges, W., & Mitchell, S. (unknown). Leading Transition: A new model for change. Available at: https://url.au.m.mimecastprotect.com/s/U351CZY1YPtAGOzmizfoUBr5eb?domain=crowe-associates.co.uk" https://www.crowe-associates.co.uk/wp-content/uploads/2013/08/WilliamBridgesTransitionandChangeModel.pdf

Chapter 4

Funding for consumer involvement

> In this section, we explore funding for consumer involvement, covering CP-Achieve approaches to:
>
> - payment of consumers
> - the CP-Achieve small grants program
> - budgeting for consumer involvement
> - tips for getting organised
> - future funding avenues.

**Carolyn Pinto,
Consumer Coordinator**

Follow this link

To hear Associate Professor Margaret Wallen and Carolyn Pinto, CP-Achieve Consumer Coordinator, talk about budgeting for the involvement of consumers with disability.

Payment for consumers

Paying consumers for their involvement acknowledges their meaningful and critical contribution to research, demonstrating both **respect** for consumers and acknowledging their **lived experience expertise**. Payment also acknowledges the time commitments required of consumers over the life of a project. CP-Achieve paid consumers at an hourly rate and included all time spent at meetings, preparing for meetings and completing other consumer research partner activities, such as testing surveys and writing and reviewing study documents and materials.

Good practice

Valuing consumer expertise and compensating them fairly for their time is crucial to fostering meaningful involvement and is considered good practice.

The CP-Achieve small grants program

CP-Achieve's small grants program enabled researchers to secure funding for consumer involvement in their projects through an **annual grant application process**.

Setting up the fund

The consumer involvement team established **procedures and selection criteria** for the small grants program. Each year, the total annual funding available (from grants and other sources such as profit from biennial symposia income) was considered against the number and amount of budget requests, equity of access to the funds, and funding priorities. During the grant application period, the consumer coordination team met with the Research Coordinator and the Principal Investigator in regular meetings.

Working documents related to these processes can be downloaded from a link in 11. Getting started: Steps for your journey.

Grant program priorities

The small grants program prioritised supporting consumer involvement **very early in the research cycle**, at a time when funding is rarely available. Involving consumers at the beginning of the research cycle delivers benefits for the research and ensures appropriate involvement costs can be reflected in project proposals.

The small grants program also prioritised funding for projects where researchers had unsuccessfully applied elsewhere for consumer involvement funds or where there was unlikely to be an alternative source of funding.

Applying for a small grant

CP-Achieve researchers were invited to apply for grants via an annual funding round at the end of the year to fund activity in the subsequent calendar year. This timing enabled consolidation of the amount of funding left over from the year alongside newly available funding for the next year. Out-of-round applications were also considered at other times.

Researchers applied for small grant funding by completing the CP-Achieve *Consumer Involvement Planning and Budget Application Form*[16], in which they outlined a plan and detailed explanation of the intended approach to consumer involvement, and a budget. Appropriate budgets for consumer involvement can be difficult to prepare as researchers may not know how long it will take to review materials or the specific needs of consumers. The Consumer Involvement team helped researchers develop **realistic budgets** and **appropriate involvement strategies**. Completing the form also contributed to researchers' understanding of and capacity to independently develop plans and budgets for consumer involvement when applying for other grant opportunities. Researchers were strongly encouraged to seek other sources of funding to involve consumers in their work.

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[16] Available in 11. Getting started: Steps for your journey

CP-Achieve considered applications for small grant funding for:

- consumer time for activities such as orientation, meeting preparation and attendance and independent work (e.g. document review, interviews)
- support workers' time for consumer involvement if not already covered by disability support funding.

Ideally, consumers are paid for all their involvement and all expenses covered. The small grant program funding pool was insufficient to fully fund all activities and therefore did not fund:

- courses or educational events
- researcher time needed for consumer involvement
- support workers' travel time or attendance at events where they are already being paid for these activities during their regular work hours
- childcare, parking, travel, accommodation, expenses, internet, refreshments, cost of education or conferences.

Consumer time for attendance and presentation at CP-Achieve's biennial symposia and travel and accommodation for interstate consumers was funded through CP-Achieve's symposium budget.

Grant amounts

CP-Achieve's initial small grants budget of $6,000 was expanded to a total consumer involvement spend of almost $40,000 over 48 grants in five years. CP-Achieve typically awarded grants ranging from $600 to $800, with a maximum of $1,680. Underspent funds from the small grants program at the conclusion of each calendar year were returned to the grant pool and reallocated to researchers submitting new applications.

Consumer payments

Consumer research partners were paid $40 per hour using electronic gift vouchers, which were sent via email and could be accessed on nearly any device. Payments for support workers were usually managed by the consumer through their individual disability support funding (e.g. through an NDIS plan[17]). The hourly rate was determined at the outset of CP-Achieve based on a scan of other consumer involvement program practices in the sector (e.g. Victorian Comprehensive Cancer Centre (VCCC) Alliance cost model) and budget modelling that considered the estimated program demand for consumer involvement.[18]

Why vouchers?

Vouchers were the most **practical solution** for CP-Achieve to pay consumers. Other forms of payment options, such as fixed term or casual employment or supplier contracts, created significant **barriers** for consumers. Barriers included the burden of engaging online for payment, requirements for insurance, completion of multiple complex forms, and the additional time needed to administer these forms of payment. Vouchers, on the other hand, **simplified** the process for everyone and were mostly well accepted. Some consumers sought support to access and spend their online vouchers. Sometimes a consumer research partner chose not to be paid, and this preference was respected.

Key learning

Organisations are required to adhere to legal and ethical frameworks related to taxation and fair work. Our advice is to liaise very early with human resources and finance departments or equivalents to ensure that payment can be established according to local jurisdictions. An example is that casual employment contracts generally add a casual loading and on-costs (administrative costs) to an hourly rate, inflating the amount that needs to be included in a budget. Organisations may have policies that create restrictions on the dispersal of gift vouchers.

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[17] The National Disability Insurance Scheme (NDIS) provides funding to eligible people with disability in Australia to gain them more time with family and friends, greater independence, access to new skills, jobs or volunteering in their community, and an improved quality of life. For more information, see https://www.ndis.gov.au/

[18] We suggest reviewing this rate based on your local context and relevant benchmarks.

> “I got a CP-Achieve grant for consumer engagement, but my consumer involvement activities were delayed until close to the end of the year, so I couldn’t use the entire funding.”

Jackie Ding,
PhD Candidate

Challenges

The key benefits of the small grants program included facilitating early-stage consumer involvement and helping to ‘get the ball rolling’. However, CP-Achieve researchers did highlight some concerns with the grant program. Some of the challenges described by researchers included:

- delays due to ethics application processes that meant delays in the commencement of consumer involvement
- postponed projects impacting the ability of researchers to utilise their grants according to their proposed schedule
- timing issues, particularly when consumer involvement activities were scheduled late in the year, leading to underspending as grants were allocated by calendar year rather than 12 months from the time of allocation
- challenges in adequately budgeting for *potential* accessibility needs (e.g. interpreting, support worker costs, etc.) that might not be needed.

Key learning

The small grants program has been vital for promoting consumer involvement but finding a balance between managing the funds (so that it is not administratively burdensome) and providing researchers with flexibility is important.

Reflection point

How can your program support researchers in accessing funds for consumer involvement?

Where are there existing small grants in your organisation, institution’s governance or policy to which a consumer involvement support fund could be added? Who are the champions that could support this proposal?

Budgeting for consumer involvement

Costs of involving consumers

Common consumer activities that incur costs are included in Table 7. Although not all costs listed below were covered by CP-Achieve small grants due to funding limitations, we recommend seeking coverage for these items, where possible. The costing examples are given in hours; we recommend you review sector benchmarks relevant to your context when determining the amount to be paid.

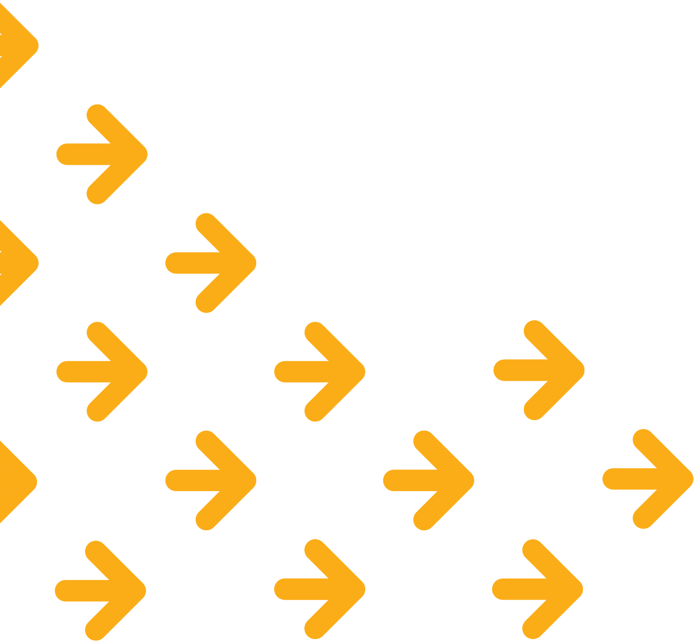

Table 7 Costs for consumer involvement

Budget items	Guidance	Costing example*
Orientation	CP-Achieve provided a generic consumer-focused orientation to CP-Achieve and consumer involvement generally. Consumer orientation to individual research projects is also critical for developing shared expectations, ways of communicating and an understanding of key activities across the research cycle.	Orientation sessions typically involved a 1.5 hour meeting with consumers.
Meeting preparation	Consumers should be paid for preparation time for meetings. This could include time to prepare thoughts and responses on communication devices.	Depending on the tasks and consumer needs, this could be 30 minutes to 3 hours per meeting.
Meetings	The number of meetings will reflect the level of influence the consumer has in the project, the scope of involvement over the research cycle and the nature and size of the project.	Meetings of 1.5 hours are typical.
Work outside of meetings, such as preparing and reviewing documents, preparing video or other content for research, attending training for the project, data collection, preparing and rehearsing presentations and so on.	Be realistic about the time consumers may need to review materials, particularly where they are clinical in nature and contain terms and concepts that may be unfamiliar. It helps when working with long documents to direct the consumers' attention to critical sections relevant to their lived experience, to assist them to prioritise the time available to them and to optimise time use and budget allocations. Consider extra time that consumers with disability might need to read, review and develop documents and other materials, including the need to use technology. Time spent on administration processes, such as compliance training, setting up personal email accounts, registering an investigator account for a grant application, and making pay claims, should also be taken into account.	This amount varied depending on the project requirements. Some researchers found that consumers preferred to discuss documents within meetings rather than comment on them outside of meetings. As such, they allocated more funding for longer meetings and between 30 minutes to 3 hours to read documents in preparation for those meetings (depending on content).

*Note any factors requiring additional budget (e.g. for support workers) or working time (e.g. for AAC users or those requiring communication assistance).

Good practice

CP-Achieve awarded travel scholarships to consumers to present at national and international conferences, as they did for doctoral and postdoctoral scholars.

Table 7 Costs for consumer involvement (continued)

Budget items	Guidance	Costing example*
Support people (for consumer research partners)	CP-Achieve funded support workers where other funding (e.g. NDIS[19]) was not available and a support worker was needed to ensure the involvement of the consumer. Support workers may be paid for supporting the consumer with preparatory activities, research activities outside of meetings, attendance at research meetings and at webinars and conferences where the consumer is presenting.	The time for support workers will be subject to the individual needs of the consumer.
Conferences	Consumers should be paid for their attendance at conferences where they are involved in the presentation as a presenter, co-presenter or panel member. Consumers should also be paid for time preparing and rehearsing for the conference presentations.	Registration fees (including social events), travel (including transfers), accommodation, meals and incidentals. Travel, accommodation, and social event/registration costs for attending support workers and carers if required. Reimbursements for time spent preparing, rehearsing for and presenting at conferences: typically four hours for every hour of presentation time (more for AAC users).
Education costs	Costs need to be covered where the project requires consumers to attend education activities.	Training costs, travel.
Incidental expenses	These costs relate to travel and costs of accessing required services/equipment.	Childcare, parking, travel, internet and other required IT equipment, refreshments.

*Note any factors requiring additional budget (e.g. for support workers) or working time (e.g. for AAC users or those requiring communication assistance).

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[19] The National Disability Insurance Scheme (NDIS) provides funding to eligible people with disability in Australia to gain them more time with family and friends, greater independence, access to new skills, jobs or volunteering in their community, and an improved quality of life. For more information, go to https://www.ndis.gov.au/

Costs for researcher time

We recommend that researchers budget the following costs (see Table 8) into grant applications, acknowledging additional time needed for consumer involvement.

Table 8 Budget items related to researcher time

Budget items	Guidance	Costing example
Preparation and follow-up	Whether it be advisory group meetings or research meetings involving consumers, preparation is critical. We suggested researchers build preparation time for meetings and managing consumer payments into their budgets. This may include preparing content for meetings in Easy Read format, preparing agendas in advance and providing meeting minutes.	For every 1 hour meeting, you may need to budget for an additional 1.5 hours for meeting preparation.
Wellbeing check-ins	Consider the time required to do wellbeing check-ins with consumers, supporting consumers to understand the research process and to build their confidence to share their opinions in meetings. During check-ins, consumers should be asked if their level of involvement meets their expectations or if they have any concerns about their involvement. As consumers are often unfamiliar with research processes and related activities, such as preparing for and attending conferences, researcher time is needed to effectively assist consumers to prepare.	This may involve between 30 minutes to a few hours monthly per consumer, depending on their experience, your administrative systems and project complexity.
Peer-based sharing and learning activities	Peer-based sharing and learning activities, such as talking to peers about consumer involvement practices, troubleshooting and involvement in organisational learning opportunities focused on consumer involvement.	Peer learning such as this is typically not reimbursed but should be recognised as a likely time commitment with resourcing implications.

Costs of involving *One Group Our Voice* in research

One Group Our Voice was a CP-Achieve Consumer Advisory Group consisting of four members who use augmentative and alternative communication (AAC). Members met every three weeks over a couple of years to collaborate with researchers and students seeking advice on working with AAC users and to work on group-specific projects. In particular, One Group Our Voice co-developed unique resources to support researchers to involve AAC users in research as participants and consumer research partners. This work culminated in a journal article and toolkit.

The authentic involvement of AAC users in One Group Our Voice required thoughtful preparation and facilitation, which enhanced the depth and quality of their contributions. As a result, the costs for engaging this group were higher than other advisory groups. For example, a one-hour research meeting typically involved seven hours of facilitation, including pre-meeting preparation of each member, accessible material development and post-meeting follow-up. Family members or support workers also played a vital role in supporting communication and technology during meetings, ensuring full participation and enriching the research process.

The Inclusive Research Toolkit, created by One Group Our Voice in collaboration with researchers, is available online to download: Click this link or scan the QR code to download a copy of the Toolkit.

Tips for getting organised

Freya, one of our consumer research partners, shared a helpful tip for tracking and streamlining her consumer payments and reducing both consumer and researcher time for administration:

> **“Having a timesheet to track our work has made it easier to manage and report. It’s helped me and Stacey (the researcher) keep things organised.”**

According to Jackie Ding, PhD candidate, it is important to add some contingency into your budget for both your own time and that of consumers:

> **“I learnt that things do take a lot longer than anticipated. So, budget for that and be clear around expectations of consumers at the very beginning.”**

Future funding options

CP-Achieve’s small grants program not only provided vital funding but also highlighted the importance of flexible, responsive processes to support consumer involvement.

Funding avenues have arisen that value consumer involvement, such as the **Cerebral Palsy Strategy**’s Lived Experience Engagement Fund,[20] and the **National Disability Research Partnership**.[21]

Researchers, however, need to include **adequately constructed budgets** for consumer involvement in **all grant applications**.

Reflection point

How can your program support researchers in accessing funds for consumer involvement?

What sources of funding are available to you for consumer involvement?

Key takeaways

Payment acknowledges the critical contributions of consumers, demonstrating both respect for consumers’ time and their lived experience expertise.

Payment for consumers in the early ‘deciding what to research’ stage is important but can be challenging and requires creativity.

Consider and apply for funding for ALL consumer involvement activities, from personnel to coordinating involvement and payment of consumers for all their time, through to conference attendance costs and support worker expenses.

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[20] https://cerebralpalsystrategy.com.au/get-involved/funding-opportunity/

[21] https://www.ndrp.org.au/

Chapter 5

Support to researchers to authentically involve consumers

> Researchers new to consumer involvement often need guidance on how to make research processes accessible to consumer research partners. In this section, Dr Sarah Giles shares her experiences of consumer involvement in her research into young people's mental health while I outline how the consumer coordinators:
>
> - provided an orientation on consumer involvement for researchers
> - facilitated connections between researchers and consumers
> - supported researchers in planning for authentic consumer involvement, providing advice and support where needed
> - assisted in budgeting and provision of small grants for consumer involvement
> - supported researchers to close the feedback loop.

Carolyn Pinto, Consumer Coordinator

Follow this link

To hear Consumer Coordinator Sevastine Katsakis explain how she supports researchers to involve consumers, and some of the key advice she has for researchers new to consumer involvement.

Research project:

Understanding the Physical and Mental Health of Young People with Cerebral Palsy

Researcher: Dr Sarah Giles

About the project: The research explored the interrelationships between the mental health of young people with cerebral palsy and their physical health; for example, how pain and fatigue affect mental health and vice versa. First, it included a literature review to identify the factors influencing the mental health of young people with cerebral palsy, such as access to community, anxiety, pain and fatigue. Then, measures of mental health conditions were selected that aligned with the main themes identified in the literature review. Finally, a national survey using the selected measures sought to determine the prevalence of mental health conditions in young people with cerebral palsy. Consumer research partners contributed to selecting measures of mental health for the survey, as well as shaping the survey's presentation, structure and promotion.

About Sarah: Sarah is a Postdoctoral Research Fellow at CP-Achieve and has some experience working with consumers. Her clinical and research background is in mental health. While doing her PhD, Sarah sought the advice of parents of young people with eating disorders to develop a survey tool.

Providing an orientation on consumer involvement

Carolyn

Recognising that consumer involvement was new to many of CP-Achieve's researchers, we developed pathways to build researchers' capacity and ensure that consumers felt valued in their involvement. We provided all researchers with an **informal orientation to consumer involvement** during online meetings with research teams, helping them decide when to involve consumers and identify an appropriate involvement approach, such as working with an advisory group and/or engaging with individual partners.

Sarah

CP-Achieve's orientation played a key role in shaping our approach. It provided an insight into **what is needed to support consumers** to actively participate during the involvement process. Simple things stood out, like providing a clear summary of what the person will be asked to do during the meeting and giving them options for participation (e.g. raising issues in a meeting or sending written feedback after a meeting).

What also stood out was how important it is to **engage at least two consumers on a project**. This is a small detail that I think made a really significant impact at a process level – consumers feeling more comfortable participating when engaging with researchers, but also at a content level – the contributions from consumers were more diverse, and members all had unique perspectives.

CP-Achieve's orientation process for researchers

The informal consumer involvement orientation, provided online to CP-Achieve research teams during one-on-one meetings and supported by the *Consumer Involvement Planning and Budget Application Form*[22], explored how and when to involve consumers and different levels of consumer influence.

It also guided researchers to:

- involve at least two consumers on each project - to share the load, seek diversity of experiences, provide support for one another and enhance the likelihood of one consumer being available when needed for collaboration
- communicate clearly about the tasks to be undertaken, time commitments, duration, any mutual expectations of involvement, and payment rate for the time invested in involvement
- ensure that they establish ongoing communication and support and build and sustain relationships, particularly when there are delays in research projects
- be flexible, responding both to consumer needs, their work and caring demands, and their priorities and perspectives
- close the feedback loop, which means communicating to consumers about how their input influenced the research and actions that were taken because of their involvement, as well as reporting and providing the final study findings in accessible formats.

Researchers were encouraged to participate in consumer involvement education through the University of Melbourne's Healthy Trajectories program. They were also offered the opportunity to attend mental health first aid training[23], equipping them with the skills to respond effectively to young people facing mental health challenges, should this occur.

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[22] This form can be accessed in 11. Getting started: Steps for your journey.

[23] Mental Health First Aid Training, provided by Mental Health First Aid International, teaches participants skills to recognise and respond to someone experiencing a mental health problem or mental health crisis, until professional help is received or the crisis resolves.

Facilitating connections to advisory groups

Carolyn

We assisted researchers to work with advisory groups in two ways. We supported them to develop **clear descriptions** of the project opportunities and then **liaised** with relevant advisory groups to assess their interest in getting involved. It was important that consumers knew exactly what they were to be involved in - including the **time commitments**, the **project duration** and the relevant **stage of research**. We also assisted researchers to develop the agenda for and then facilitate meetings with advisory groups. The timing of requests from researchers was often difficult to predict and, at times, infrequent due to research timeframes and progress. As we had strong relationships with advisory group members, we usually attended and **directly facilitated** meetings to ensure a sense of safety, confidence and continuity for consumers – particularly for younger advisors.

Sarah

We involved CP-Unite[24] and the Parent Advisory Group[25] in our research rather than work with individual consumer research partners to ensure a broad range of perspectives from young people with cerebral palsy.

Recognising that discussing mental health can be challenging, we hoped that group discussions would shift the focus from personal experiences to identifying what would be most beneficial for young people with cerebral palsy more generally. This approach not only provided a diversity of insights but also fostered a safer, more supportive environment for addressing sensitive topics.

Matching individual consumer research partners to projects

When CP-Achieve researchers wanted to work with individual consumer research partners, the consumer coordinators' role was to match consumer research partners to projects that fit with their skills, interests and availability. This necessitated a deep understanding of the consumer's interests and priorities, and liaison with researchers to identify an appropriate match.

Once matched, the consumer coordinators facilitated introductions and initial meetings between consumers and researchers, and then researchers managed the relationship with consumers, and ongoing research activities and meetings.

The process for matching consumers and research projects is outlined in more detail in 8. Building authentic relationships.

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[24] A CP-Achieve advisory group of adults with cerebral palsy aged 18–30 years.

[25] A CP-Achieve advisory group of parents and carers of young people with cerebral palsy.

Planning for authentic consumer involvement

Carolyn

We developed and refined a ***Consumer Involvement Planning and Budget Application Form*** to help researchers thoughtfully plan how, when and why they would involve consumers in their projects. This allowed for a budget to be developed to pay consumers for their involvement. The form also encouraged the researchers to consider **communication strategies** with consumers, ways to **collaborate** effectively, and how to **acknowledge** consumer contributions to ensure consumers' perspectives were heard and respected.

Beyond planning and budgeting, the form facilitated **discussions** between researchers and the Consumer Involvement team, **fostering learning** about best practices and offering examples of consumer engagement across different stages of the research cycle. It also provided **practical guidance** for budgeting and served as a request form for consumer-researcher partnerships and small consumer involvement grants, where needed.

Sarah

We determined that the **key opportunities** for consumer involvement were in the design stage of the research cycle. We wanted consumer advice on the selection of measures included in the survey and on shaping the presentation, structure and promotion of the survey. To facilitate the involvement of the two advisory groups, the research team hosted two webinars supported by the consumer coordinators and shared the survey via email for feedback. More details about consumer involvement in this project are given in Table 9.

Table 9 Consumer influence in Sarah Giles's research

Stage of the research cycle	Research activity	Consumer roles
Designing the study	Development of survey scope and questions, and recommendations for approaches for advertising the survey to optimise uptake	Members of CP-Unite and the Parent Advisory Group: • shared their experiences of cerebral palsy and mental health during a two-hour webinar. This advice was used to shape the content of the survey • provided verbal feedback on the proposed survey questions during a second webinar and on the survey's presentation and structure • provided written comments on the proposed survey • provided written feedback on advertising materials (sent in PDF format via email) to promote the survey.

Advice and support

Carolyn

The Consumer Involvement team offered on-request advice, guiding researchers through how the key concepts in the *Consumer Involvement Planning and Budget Application Form* applied to their specific projects. We encouraged researchers to be **flexible** when working with consumers. This included offering different ways to engage, accommodating their availability and ensuring ongoing communication. We also recommend **closing the feedback loop** – communicating to consumers about how their input influenced the research and ensuring that consumers received the overall study findings in an accessible way.

Sarah

Initially, I didn't know what the needs of CP-Unite would be and how I might best support those needs. I found it extremely helpful having someone like Sevastine, who **knew the participants** really well and could explain to me how to **engage them** and make the process **accessible** for them.

I learnt from working with the consumer coordinators that it is very important to give people the opportunity to make **informed decisions** about their collaboration. Discussing lived experiences of mental health challenges is deeply personal, and we wanted to ensure consumers could engage on their own terms. That's why we gave all consumer research partners a **primer** on the research topic and an option to **opt out** before or during the webinars. We also provided the research team's contact details for any follow-up support. Some young people chose not to participate because they didn't feel comfortable, which reinforced the importance of giving people a **choice** in their involvement.

We were encouraged to be **flexible** in our approach to working with consumers. To accommodate different preferences, we offered the advisory groups the option to provide feedback in writing or through facilitated discussions in our webinars. The webinar format seemed less overwhelming for young consumers, as it allowed us to guide them through the survey questions in real-time.

Reflection point

What flexible involvement options can you offer consumers?

What could be the sensitive issues or touchpoints in your research to be aware of and approach in a trauma-informed manner?

Do you know where you could get support and advice to ensure your approaches are trauma-informed?

> **The Consumer Involvement team highlighted the importance of making sure that our approach to collaboration with consumers is trauma-informed.[26]**

Dr Sarah Giles, Postdoctoral Research Fellow

> **To truly benefit from consumer involvement, researchers must value diverse perspectives and remain flexible. Often this will mean adapting their initial ideas and concepts to align with the priorities of those with lived experience.**

Carolyn Pinto, Consumer Coordinator

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[26] Trauma-informed practice recognises that consumers may be affected by trauma and is centred on empowering, strengths-focused, collaborative and reflective approaches.

Funding for consumer involvement

Carolyn

In a survey of researchers conducted during the final year of the CP-Achieve program, researchers ranked the provision of small grants for consumer involvement among the top three most valued services offered by the Consumer Involvement team. The high priority placed on this funding highlights the importance of easily accessible, early stage funding for consumer involvement, and the significant challenges researchers typically face in **securing this funding**.

Read more about how to budget for consumer involvement and our small grants program in 4. Funding for consumer involvement.

Sarah

In 2023, we submitted a grant application to CP-Achieve's small grants program for $1,480. This funded our consultations with advisory groups and demonstrated to consumers the value we placed on their involvement. The breakdown of the funding is in Table 10.

Table 10 Sarah Giles's investment in consumer involvement

Activity	Consumer involvement (including preparation time, meetings, materials development and document review)	Researcher time to prepare for and support consumer involvement (approximate)
Webinar #1: initial discussion of mental health and research goals	3 hours x 3 advisors = **9 hours**	4 hours x 2 researchers = **8 hours**
Webinar #2: Review of survey questions	3 hours x 8 advisors = **24 hours**	1 hour x 1 researcher = **1 hour**
Home-based review of survey questions	2 hours x 2 advisors = **4 hours**	4 hours x 2 researchers = **8 hours**
Total time	37 hours	17 hours
Total cost	$1,480	

Reflection point

What funding for consumer involvement can you access in your institution or through grant funding?

How can you ensure funding is available for consumer involvement in the early stages of your research?

Practical templates

Carolyn

We provided **templates and guidance** to researchers on request, such as examples of accessible presentations, documentation and meeting plans. Researchers found these templates incredibly valuable in formulating their engagement with consumers.

Sarah

One template we found really useful was the **Meeting Plan**. It helped us structure discussions, allocate time effectively and ensure consumers knew what to expect from the webinar. Sharing the meeting plans two weeks before the webinars gave the consumers time to prepare, making discussions more productive.

This Meeting Plan can be accessed in the Working Examples in 11. Getting started: Steps for your journey.

Reflection point

What tools, templates and guidance do you need to involve consumers authentically?

Closing the loop

Carolyn

A key principle of our consumer involvement is **reporting back** to consumers on how their ideas, feedback, and work influenced research processes and outputs and explaining any barriers to implementing their inputs. We call this closing the loop.

Sarah

As with all consumer advice and feedback, it can be challenging when you are not able to take on board all the suggestions made by consumers. In this project, consumer research partners suggested providing financial incentives to survey participants, but we didn't have the funding. To **acknowledge their input**, we created a visual list of their recommendations, marking those we could implement and discussing why some weren't feasible. It was a tough conversation, but it was important to show that their voices were heard.

Key learning

We recommend all researchers, particularly those who do not have a consumer involvement support team, attend mental health first aid training before working with consumer research partners with disability or their families. This is in recognition of the higher prevalence of mental health concerns among young people with disability and their parents and carers.

Troubleshooting

Many researchers sought advice on day-to-day relationship development and operationalisation of consumer involvement from peers and supervisors. On occasions, however, researchers reached out to consumer coordinators to address more complex challenges. For example, a few researchers raised concerns about their duty of care and managing professional boundaries with young consumers who faced mental health challenges and were reaching out for support.

Setting boundaries

We encouraged discussions around boundary setting between researchers and consumers and set clear expectations regarding communication when it is unrelated to the research projects. Researchers were coached to communicate to consumers how they would receive responses to requests – whether via phone or email – and at what times they could expect those responses. This ensured that consumers felt guided and understood in the communication process, fostering a more organised and respectful interaction.

Managing duty of care

Consumer coordinators advised researchers on how to manage scenarios that were outside their role and organised for interested researchers to attend mental health first aid training.[27] This gave researchers the confidence and skills to respond effectively in instances where consumers had mental health issues.

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[27] The mental health first aid training, provided by Mental Health First Aid International, teaches participants to recognise and respond to someone experiencing a mental health problem or mental health crisis until professional help is received or the crisis is resolved.

Impacts of consumer involvement

Carolyn

We see significant impacts of consumer involvement across the program – not only in terms of research outcomes but also concerning researchers' skills and perspectives.

Sarah

Consumer involvement was invaluable in helping us design a survey that addressed both the key mental health **issues important to young people** with cerebral palsy and the often-overlooked aspects of their mental health. It also gave me a **deeper insight** into the lived experiences of this group, **reaffirming** that the mental health of young people with cerebral palsy is frequently overlooked and under-recognised - an insight that strongly supported our research goals.

One significant takeaway from CP-Unite was that young people with cerebral palsy often struggle to have their mental health concerns acknowledged or validated by healthcare professionals. This wasn't something we had considered, as our focus was primarily on the prevalence of mental health conditions. Learning, anecdotally, that these young people face complex barriers to accessing appropriate mental health support made us realise we lacked a clear understanding of which professionals need further education to effectively support this population. This insight has since **guided us to develop a new project** aimed at systematically exploring these barriers.

CP-Unite also emphasised the need to **make survey questions accessible** for young people with complex communication needs. In response, we added a brief explanation before each question, clarifying what it was asking and why it was relevant. We also included video and audio recordings of these explanations so respondents could choose to listen if that was easier for them.

The Parent Advisory Group highlighted that developmental delays associated with cerebral palsy might affect how clinicians recognise anxiety. For instance, while clinicians might look for signs of social anxiety in a teenager, developmental challenges might mean that the anxiety presents more like separation anxiety. Parents felt clinicians' questions often didn't align with the child's developmental stage.

Parents also expressed a desire for their young people to be represented in the survey, even if they couldn't self-report due to communication difficulties or intellectual disability. To address this, we ensured all the measures had a **proxy report** option, allowing parents to respond on behalf of their children.

We also received feedback that it would be beneficial to feature someone with cerebral palsy in our advertising and communication materials to boost respondents' participation in our survey. So, we created a video featuring young people with cerebral palsy discussing why they felt the survey was valuable.

Reflection point

How will you work with consumers to identify relevant accessibility needs for your research?

Key takeaways

Resources and support to enhance the researcher's confidence and authentic consumer involvement practices include:

- education about consumer involvement principles
- connections to consumer networks, advisory groups and individual consumers joining research teams
- access to advice and funding.

Publications

Sarah's research results have not yet been published. Findings have been presented at the following conferences:

Giles, S., Imms, I., Shields, N., Holmes, C., Coghill, D., Reddihough, D. (2024). Exploring the Mental Health and Wellbeing of Young People with Cerebral Palsy. Presentation accepted at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Cairns, Australia. August 1-3.

Giles, S., Holmes, C., Imms, I., Coghill, D., Tracy, J., Dutia, I., Mulraney, M., Eres, R., Reddihough, D. (2024). Understanding Health Profiles and Clinical Characteristics of a Cohort of Young Australians with Cerebral Palsy. Poster accepted at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Cairns, Australia. August 1-3.

Chapter 6

Building community and a sense of safety for consumers: Working with adolescent advisors

> “Working with young people with disability and families as consumer research partners requires processes that are engaging, value lived experience, build community and promote psychological safety and wellbeing. Here, I will show how CP-Achieve applied these concepts in practice while developing and supporting the CP-Voice Advisory Group. I will discuss how we:
>
> - recruited and onboarded members
> - got to know consumers and parents
> - created a sense of belonging and community
> - created accessible online meetings that were fun
> - promoted feelings of safety and support
> - linked consumer research partners with mentors
> - transitioned consumers at the end of CP-Achieve.”

Sevastine Katsakis, Consumer Coordinator

Follow this link

To hear Sevastine Katsakis and Carolyn Pinto, CP-Achieve’s Consumer Coordinators, talk about creating community and a sense of safety for all our consumer research partners.

About CP-Voice

CP-Voice was a group of six adolescents with cerebral palsy aged between 10 and 18 years who formed an advisory group for CP-Achieve. The advisory group was established in 2021 to ensure researchers had access to consumer guidance from adolescents to inform the initial stages of their research while securing funding for ongoing and more extensive involvement.

We believed that, while young, these consumers had the right to be heard on research that would impact them, and that their lived experience expertise and insights would drive more rigorous, meaningful and quality outcomes.

CP-Voice initially contributed feedback on the research program's themes and priorities and later provided direct feedback and advice to 10 CP-Achieve research projects.

Recruiting and onboarding CP-Voice members

Recruitment and onboarding are important mechanisms for fostering a sense of belonging and partnership with young people and their parents. Ensuring safety through adherence to the National Principles of Child Safe Organisations was a key priority. We welcomed adolescents with all presentations of cerebral palsy, all backgrounds and from all Australian locations to become advisors and we were committed to ensuring accessible opportunities.

Our process included several key steps to provide information, discuss involvement, build trust and get to know the young person and their family. We:

1. invited young people to express interest in joining the Advisory Group via the CP-Achieve Consumer Network. Interested consumers provided their details through an online form
2. conducted a 'meet and greet' call with the young person and their parent to discuss the involvement opportunity
3. followed up with an email containing relevant documents (e.g. CP-Achieve welcome pack)
4. invited interested young people and their parents to an orientation session
5. sent a follow-up email with the 'agreement to be involved' form, seeking the young person's agreement to be involved and parental consent. Once the form was returned, the young person was officially a consumer advisor.

CP-Achieve

Calling young people with CP
CP-Achieve needs your help!
Adolescent Advisory Group

Are you a young person with cerebral palsy, aged 10 to 18 years? Make a difference!

Join an Advisory Group of other young people and add your voice to CP research.

You can make your voice count by telling us what's important to you.

To express your interest use the QR code or go to our website: cp-achieve.org.au

CP-ACHIEVE
Centre of Research Excellence
Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with Cerebral Palsy

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> **We recognised that parents play a dual role as key supporters of their child's involvement while also acting as gatekeepers, ensuring their safety and wellbeing. They need to be involved in every step.**
>
> **Sevastine Katsakis,**
> **Consumer Coordinator**

In practice, while CP-Voice advisors came from multiple states across Australia, they did not have a diversity of cerebral palsy experience; most had mild presentations of cerebral palsy and communicated using verbal methods. They were also of similar cultural backgrounds.

Good practice

Adhering to the National Principles of Child Safe Organisations.

Key learning

We recommend explicitly inviting young people with significant support needs to adolescent advisory groups to build inclusion and ensure that a diversity of perspectives and experiences is informing research. For guidance on working with augmentative and alternative communication (AAC) users, go to 9. Working with young adults who use augmentative and alternative communication.

Reflection point

If you intend to involve adolescents as consumer research partners in your research, how will you build their sense of safety and community?

How will you engage with parents to build their confidence that their adolescents will be safe being consumer research partners in your research?

Getting to know consumers - creating consumer profiles

At the end of the onboarding process, before the advisory group convened, we invested time in getting to know the CP-Voice advisors. We worked collaboratively via email to create profiles[28] for each young consumer that documented their interests, hobbies and support needs. Short versions of the profiles (excluding support needs, which were confidential) were made available on the CP-Achieve website.

Ivy, one of our CP-Voice advisors joined the group at only 10 years of age. This was her public profile:

Ivy is a 10-year-old girl who has cerebral palsy. She loves drama lessons and performing on stage. She also loves swimming, watching movies and hanging out with her friends. Ivy lives at home with Mum, Dad, a big brother and a little sister. She has five chickens.

When CP-Voice advisors joined research projects, full profiles were shared and discussed in one-on-one meetings with the researcher to ensure alignment with project interests and goals and that support needs were met.

We kept in regular communication with CP-Voice advisors. Some of the younger advisors did not have access to their own phones or email accounts. We suggested the use of the secure platform, Messenger for Kids, which was easily adopted, with parents able to monitor communication while also promoting their young person's independence. Text messaging was also a common form of communication for advisors with their own phones (typically those aged over 16).

> “Feeling known and valued is important for the development of consumer confidence and willingness to engage in research.”
>
> **Sevastine Katsakis, Consumer Coordinator**

Reflection point

How can you build a deeper understanding of your consumers' strengths and needs?

What support can you provide to promote their active involvement and help them overcome potential barriers?

How will you promote independent communication with young people while balancing the need for parental supervision and permission?

How will you celebrate their involvement in your research?

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[28] The profile format can be accessed in 11. Getting started: Steps for your journey.

> “At the start of CP-Voice, parents often appeared on screen with their child, speaking on their behalf or encouraging them to engage. This reflected both consumer and parent nervousness, with many parents seeking to protect their child from discomfort. As young consumers gained confidence and saw their opinions valued by researchers, and as parents became more comfortable with the process, they gradually stepped back, creating more space for their young person’s agency and enjoyment.”

Sevastine Katsakis,
Consumer Coordinator

Working with parents of adolescents

Parents were often advocates for their young person’s involvement in CP-Voice. For example, one parent of a quieter member reached out to strategise ways to boost their child’s confidence and encourage them to contribute their own ideas.

While dedicated to supporting their young person’s involvement in research, parents were also mindful of ensuring the process was safe, respectful and empowering.

At the program’s outset, I focused on building trust with parents, often through empathetic conversations that encouraged them to share experiences of parenting a child with cerebral palsy. Most attended initial CP-Voice meetings, staying in the background to offer support when needed. As this trust deepened, so did their support for their child’s independent participation.

I kept parents regularly updated on their child’s involvement through email. In every CP-Voice meeting, I made sure to acknowledge the parents’ support and offered opportunities for feedback, collaboration and troubleshooting along the way.

Good practice

Involving parents in the process of involving their young people.

Reflection point

What can you do to build a relationship and gain the trust of parents and their young people?

Building a sense of community and belonging in CP-Voice

Early on, the group self-selected a name, sharing their hopes and practising collaboration. CP-Voice advisors' profiles were shared with each other to identify common interests and reduce initial online awkwardness. I hosted non-research meetings to foster relationships, community and continuity during periods of low research activity. Ten social events, such as trivia nights and 'getting to know you' sessions, were organised with support from two volunteers. CP-Achieve also held annual online Christmas parties. I kept track of members' latest news and interests to demonstrate my care and value for each individual.

Reflection point

What opportunities exist to create a sense of community in your consumer network?

> “CP-Achieve consumer involvement practices are enhanced by the sense of family that we have been able to create in and amongst our partnerships and the community network.”

Sevastine Katsakis, Consumer Coordinator

> “Ivy often speaks of not feeling useful and preferring days when she has a purpose. I see that when she is contributing to groups like CP-Voice, it gives her that. It has made something that can be seen as a deficit [cerebral palsy] into a resource that gave her value.”

Michelle Roger, speaking about her daughter Ivy, who was a member of CP-Achieve

Facilitating online advisory group meetings

Meeting preparation

Draft agendas in Plain English, using a consistent format that featured visuals and was screen-reader friendly, were circulated two weeks prior to all meetings. Advisors were invited to add items to the agenda before it was finalised. I also contacted each group member individually to discuss the purpose and content prior to each meeting. Mentors were available for interested consumers and assisted them in preparing for meetings. In some cases, consumers asked me to present their ideas for them in group meetings.

Reflection point

How will you prepare consumers for research activities such as meetings and workshops, recognising that young people with disability may need scaffolding to develop confidence and agency?

Accessibility

To optimise the accessibility of meetings, agendas were designed with realistic timing, and the pace was managed closely to meet the needs of all advisors. Interpreters were provided for a member who had a hearing impairment; support workers were funded by NDIS to take notes and/or manage the technology; and materials were supplied in Plain English format. Most meetings were held at night to accommodate consumer availability.

Various flexible working methods were provided, and information was customised to ensure accessibility for all consumer partners. This included delivering research communications in formats that were easy to read and understand, such as compatibility with screen readers and captions during online meetings.

Zoom was the chosen platform for group meetings due to its accessibility features, such as closed captions (which were enabled in all meetings) and adaptable colour contrast, which was used to improve accessibility for advisors with low vision. Advisors without a computer were encouraged to call into meetings on a mobile phone.

Reflection point

What can you do to support the involvement of all consumer research partners in meetings, recognising the diversity in disability and support needs?

Ground rules

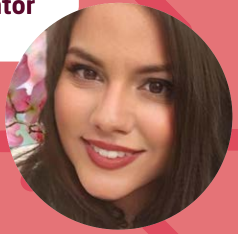
CP-Voice ground rules and practices were established and revisited at every meeting to promote a respectful and productive environment.

Initially, two 'team leaders' from CP-Voice were asked to volunteer for each meeting to act as peer mentors, encouraging other advisors to participate and contribute. Over time, these roles were no longer needed as advisors were comfortable contributing.

In addition to ensuring everyone got a chance to speak in meetings, I worked to encourage a culture of peer support. Each speaker was asked to share something they liked about what the speaker before them had said and to choose the next person to speak. I also made use of Zoom breakout rooms at the end of the call (for 5-10 minutes) for the advisors to have social time with each other. While we worked to adhere to the allocated time, if more time was needed, advisors were invited to discuss their thoughts with us or provide additional comments via email after the meeting.

> **"Without any guidance, team leaders took to the role, validating what younger people would say and encouraging them to speak up and share their ideas."**

Sevastine Katsakis, Consumer Coordinator



> **"Ivy gets super frustrated when people talk to her in a condescending or baby-talk way. She has never experienced this in CP-Voice. This is a refreshing change."**

Michelle Roger, speaking about her daughter Ivy, who was a member of CP-Achieve

Making advisory work fun

Consistent with the age and stage of CP-Voice advisors, we worked to make meetings entertaining and enjoyable. Email communications typically used a lot of visual content as well, with few words. Each meeting was initiated with an icebreaker. Interactive whiteboards were used during discussions, including the software Mural, and tools like polls. I always acknowledged birthdays, particularly during the COVID-19 years. Advisors were encouraged to use emojis during the discussion and speak in the chat function.

Reflection point

What meeting formats and content would entertain and sustain the interest and involvement of your consumer research partners?

Promoting feelings of safety and support

Due to the age and vulnerabilities of CP-Voice advisors, it was essential to pay close attention to their mental health and safety. Some steps that I took included:

- limiting researchers to no more than two per meeting to reduce potential power imbalances
- establishing code words at the start of each meeting to signal if content became overwhelming. Advisors could also create private code words with me for confidentiality. When these words were used, the discussion would move swiftly to the next topic
- encouraging advisors to message me privately via chat if they had concerns
- monitoring for any advisor turning off their screen or microphone, which prompted a follow-up after the call to check their wellbeing.

Good practice

Prioritising and planning for the psychological safety of consumers.

Reflection point

What can you do to facilitate the safety and support needs of young people, recognising that some research topics can be traumatic and stressful due to past medical interventions and personal experiences?

What can you do to minimise any power imbalance between researchers and young people that may occur due to their age, experience of discrimination and/or prior experience with clinicians?

> “Code words were often specific fruit, or chocolate or other everyday items that could be massaged into a sentence if needed.”

Sevastine Katsakis, Consumer Coordinator

Mentoring CP-Voice advisors

CP-Achieve established a mentor program in recognition of the ways in which factors such as age, limited research experience, previous discrimination, medical trauma or power imbalance can result in suboptimal consumer involvement, particularly for young adults and adolescents with disability.

The mentor program aimed to develop the skills and confidence of consumer research partners for approaching their roles and optimising the impact of their involvement with researchers. The scope of services provided by mentors included:

- reformatting research material to improve accessibility
- explaining information, terminology or research processes
- providing support to access technology necessary for the research process
- supporting consumers to reflect on and prepare responses prior to meetings or provide feedback on documentation
- building the confidence of the consumer to share opinions through encouragement and reassurance
- being a silent attendee at research meetings on request to better understand the content for debriefing activities.

Mentor opportunities were offered to CP-Voice, CP-Unite and other young advisors at the outset of the consumer involvement program on an opt-in basis. Carefully vetted mentors were matched with consumer research partners with similar interests and given an orientation on consumer involvement, before reaching out to meet their mentee. The intention was that mentors would meet online regularly with advisors to support their role as consumer research advisors.

While there were examples of strong relationships developed and support provided, an evaluation identified the need for greater levels of resourcing and support by CP-Achieve for mentors and consumer research advisors to build relationships and achieve more consistent outcomes.

Key learning

Mentor programs require significant resources for training, introductions, relationship-building activities and progress tracking to ensure they achieve their intended goals. Further, mentors would benefit from skills in setting boundaries in relationships, and mental health first aid.

Research contributions of CP-Voice

CP-Voice Advisors and advisors from CP-Achieve's other groups contributed significantly to CP-Achieve research outcomes. Their involvement, captured in Table 11, increased over the five years as researchers gained confidence to work with them and relevant projects progressed.

Table 11 Contributions of CP-Voice to CP-Achieve's research program

CP-Voice's advisory work
• Provided feedback on thematic focus areas of CP-Achieve at the program outset • Contributed perspectives on NDIS reform for policy recommendations • Contributed ideas to a study on the transition to adulthood of young people with cerebral palsy • Informed the design and implementation of a physical and mental health survey • Provided feedback and ideas for a mental health toolkit for young people with cerebral palsy • Contributed ideas to an online Health Literacy Module in key life areas for CP-Pathfinding research

Key learning

Researchers consulted CP-Voice less than they did other advisory groups. This may be due to CP-Achieve's research focus (on transitioning to adulthood) and initial doubts held by researchers about adolescents' potential to contribute to research.

Key takeaways

Early and transparent communication about consumer involvement roles and mutual expectations is important.

Orientation and preparation are crucial and include using various strategies to get to know adolescent consumers and their parents.

Attending to meeting preparation, dynamics, accessibility, fun and inclusion will build a sense of community and optimise consumer experience and outcomes for research.

Social activities can be used for periods of low research activity to build and maintain connections among consumers and with the research program.

Chapter 7

Involving consumers across the research cycle: Co-developing an online health literacy module

> Consumers were involved in CP-Achieve projects in a range of ways across a continuum, from being informed about research to acting as ‘Equal Partners’ in research teams. Here, CP-Achieve researcher Jackie Ding, Consumer Research Partner Michelle Roger and I discuss different ways consumers were involved in developing an online health module for young people with cerebral palsy and, more broadly, in CP-Achieve, exploring:
>
> - levels of influence consumers can have in research
> - selecting influence levels and identifying consumers for projects
> - benefits and impacts of different levels of involvement
> - promoting accessibility and a sense of safety in this research
> - funding for consumer involvement
> - challenges faced and advice for researchers.

Carolyn Pinto,
Consumer Coordinator

Follow this link

To hear PhD Candidate Jackie Ding discuss her project and the different ways consumers were involved.

Research project:

Enhancing health literacy for young people with cerebral palsy (CP) in early adulthood: Co-design of a web-based educational module.

Researcher: Jackie Ding

Consumer research partner: Michelle Roger

About the project

This two-year project aimed to enhance health literacy among young adults with cerebral palsy through the development of an online health literacy module titled *CP-Pathfinding: Your health*. After conducting focus groups that identified a need for this module, Jackie formed a working group with consumer research partners (young adults with cerebral palsy and parents) and clinicians to develop the module. Once finished, the module will be tested with young people with cerebral palsy before being launched.[29]

About Jackie and Michelle

Jackie completed a Master of Public Health in 2020 and joined CP-Achieve as a PhD candidate in 2021. Michelle is a consumer research partner, bringing her lived experience as a parent of a young person with cerebral palsy. Prior to this work, Michelle worked as a pathology laboratory scientist, travel agent, pharmaceutical drug representative and high school teacher.

Neither Jackie nor Michelle had experience of consumer involvement before CP-Achieve. Since starting her PhD research, Jackie has involved young adults with cerebral palsy in decision-making throughout the project. Michelle has been involved in the CP-Achieve Parent Advisory Group and has worked on several research projects as an individual research partner.

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[29] At the time of print, the module was not yet complete.

Planning for consumer involvement: Understanding levels of influence and opportunities in the research cycle

Carolyn

We developed the *Consumer Involvement Planning and Budget Application Form*[30] to assist researchers to reflect on ways to involve consumers across project activities and as an entry point to engaging with the consumer coordinators. This application form highlighted different levels of involvement (adapted from McKenzie[31] and summarised in Table 12) across a continuum from being Informed about research to being Consumer-led.

Table 12 CP-Achieve's levels of consumer influence

	Informing	Consulting	Advise	Equal Partner	Consumer-led[32]
Level of consumer influence in a research project	Information about CP-Achieve research and consumer involvement opportunities and achievements was made available to the Consumer Network via social media, webinars and bulletins	CP-Achieve sought the views of consumers about a research activity on a once-off basis. For example, by requesting input from the CP-Achieve Consumer Network	CP-Achieve sought the advice of consumers over several points of a project. For example, research teams met with one or more of the advisory groups	Consumers worked with researchers on an equal basis to plan, design, implement and/or disseminate the results of research	Consumers took the initiative for leading and making decisions for the research

Consumer influence is often not clear-cut or linear; there can be a cross-over between categories in the continuum, changes in levels of influence over the period of a project, and opportunities to involve different consumer groups at different levels in differing stages of the research cycle. Although we aimed for consumers to be involved in all stages of the research cycle, with strong levels of influence, we also believed that it is important to take the first step, do what can be done with the resources available, learn from the experience and subsequently aim for more influential consumer involvement.

Through the *Consumer Involvement Planning and Budget Application Form*, researchers were prompted to reflect on how, why and when they would involve consumers in their project and the budget they would need to do so. The form also functioned as a mechanism to request support to identify consumer research partners and as an application for Small Grant Program funding.

Jackie

Regular communication with the consumer coordinator – whether via email or Zoom – was valuable for discussing upcoming engagement opportunities with consumers. It is also important to start planning for consumer involvement early. Because selecting the right consumers, aligning interests and availability and completing the onboarding process can take time, allowing sufficient lead time ensures a smoother engagement process. Completing the planning and budget form really helped in the planning process as the questions were very comprehensive, requiring careful consideration of consumer involvement needs.

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[30] For a working example of this form, go to 11. Getting started: Steps for your journey

[31] McKenzie A., Hanley R. (2014) Planning for consumer and community participation in health and medical research: A practical guide for health and medical researchers.

[32] While this was on our continuum, there were no consumer-led projects in CP-Achieve.

Levels of influence in CP-Achieve

Most consumer influence in CP-Achieve occurred at the 'Consulted', 'Advise' and 'Equal Partner' levels; there were no 'Consumer-led' projects. As well as exerting significant influence on design and implementation of research, consumer research partners contributing as Equal Partners presented at conferences and co-authored journal articles. One consumer, Rohan Symonds, was awarded the Churchill Fellowship to contribute to and extend the work of his research team. Along with equal-partner arrangements, advisory groups can deliver significant benefits to researchers and consumers.

While higher levels of consumer influence from the project outset (e.g. Equal Partner or Consumer-led) are ideal, they are not always feasible due to resource constraints. Researchers may face limitations from grant budgets and timelines. At the same time, consumers' availability and contributions may be affected by their commitments (work, study, volunteering, relationships, navigating health and disability services), health concerns and the extra time required to manage life with a disability. We recommend approaching consumer involvement flexibly – maximising available resources and respecting consumer constraints while adhering to principles of authentic involvement.

Identifying consumers

Carolyn

Jackie requested the involvement of one to two consumer research partners who were young adults (18+) from any location, with any experience of disability regardless of support needs. In her application, she specified that meetings would be online, likely starting date, frequency of meetings and type of work involved. We used this to identify appropriate consumers, suggesting the involvement of a parent alongside young adults to provide another perspective.

Jackie

I decided to involve consumer research partners in **two ways** in my project: as advisory groups to provide specific feedback at key points and as 'Equal Partners' in the working group established to design the *Your health* module.

Michelle

When I saw the project description, I could tell it was a good match for my interests. I have a science and teaching background, along with experience navigating the healthcare system for my daughter with cerebral palsy. I am very committed to ensuring that my daughter's transition to adult healthcare services is well supported, so working on these materials is one way to ensure that happens.

Consumer influence in project activities

Carolyn

Jackie's project is interesting because it involves **multiple layers of consumer influence**, showing what is possible when budgets and timeframes allow. While this is encouraged, it is not always achievable – resources and consumer availability can affect involvement levels.

Jackie

Understanding that **early involvement** produces better outcomes, I started involving consumers at the Design Stage of the research cycle (see Table 13).

Involving consumers in the working group as **Equal partners** was core to the project design. Recognising lived experience is essential to shaping meaningful and effective outcomes, I wanted consumers to **share decision making** for the *Your health* module. I strongly believe their involvement ensured that the research outputs were not only inclusive but also relevant to the people that they aim to serve: the end product will be fit for purpose.

Consumer research partners on the working group, like Michelle, had the same role as other members of the research team – we worked together on an **equal footing**. Everyone equally influenced outputs, had an equal say and equally valued contributions.

Michelle

My key contribution as a member of the working group has been the **analysis** of the supports and content that are useful for inclusion in this resource. I also **proofread and edited** the document, adjusting the language, style and delivery, and identifying gaps in the content.

> Consumer involvement is really important to me as it ensures the outputs are relevant and fit for purpose. Ultimately, the research is for young adults with cerebral palsy; they are the ones who benefit from it.

Jackie Ding,
PhD Candidate

Table 13 Consumer influence across the research cycle in Jackie Ding's research

Stage of the research cycle	Research activity	Consumer role
Designing the study	Focus groups with young people with cerebral palsy to explore demand for an online health module	**Consumers as *Advisors*** Consumer research partners with cerebral palsy (Greg and Gaurav): • reviewed focus group questions • assisted with interpretation of the focus group results • reviewed the slide deck provided as pre-reading to focus group participants, adjusting fonts and content to be easier to read • ensured the summary of the findings was presented in a way that was easily understood by other young adults with cerebral palsy.
Implementing the study	Development of health module content	**Consumers as *Equal Partners*** Consumer research partners with cerebral palsy (Liem, Nicole, Sophie) and a parent (Michelle) worked alongside clinicians in fortnightly working group meetings to develop, review and adjust module content.
	Feedback on completed content	**Consumers as *Advisors*** Consumer research partners with cerebral palsy (Kyra, Kai) and parents (Helen, Kylie) took on the advisory role of 'Content Reviewers'. **Consumers as *Equal Partners*** The working group reviewed feedback and used a consensus process to decide which points would be adopted in the module.

Reflection point

The involvement of consumers at multiple levels is encouraged but not always achievable. It is important to develop authentic involvement approaches that match available resources and consumer availability. How many consumers, at what stage of the research cycle and with what kind of influence are feasible in your research activities?

Closing the loop

Jackie

To highlight the impact of consumers on project outcomes and to share results, I circled back to consumers to:

- provide opportunities for any final input into the design of the module
- share the final module weblink with the consumer advisers and working group members so they could see the finished product of their hard work
- provide Certificates of Participation to the young adult consumer advisors as a way of recognising their contributions to the project.

Good practice

Closing the loop by sharing results and highlighting the impact consumers have made on a project is critical to authentic consumer involvement.

Benefits of consumer involvement

Jackie

For me, the key benefit of involving consumers in the research was the **diversity of ideas** presented by the group and the knowledge that the resulting *Your health* module would be **fit for purpose**.

Michelle

The key benefit for me was a sense of personal empowerment and contributing to something outside of my family, and feeling like **someone values what I have to say.** I also made some **new connections** with other consumers that led to discussions about other research opportunities.

> “From a consumer perspective, involvement in this project is good practice. Consumers have been involved from the get-go; then, there is a second round of consumer opinions to gain real understanding. It has been a really good experience.”

Kylie Brown, Consumer Research Partner, parent

> “I think when people think of involving consumers, they think of it as really – I don’t know if scary is the right word but – unfamiliar perhaps or involving a lot of work and a lot of coordination. And it is, but the end product is really worth it.”

Jackie Ding, PhD Candidate

Impacts of consumer involvement on the research outcomes

Carolyn

Here, Jackie and Michelle provide examples of the different types of influence consumers had on the project. We can see that consumer research partners influenced both the content and the tone of the materials.

Jackie

During working group discussions, it became clear that grounding health literacy concepts in **real-life experience** would increase the value and accessibility of the *Your health* module to people with cerebral palsy. One of the young consumers with cerebral palsy came up with the idea of including **lived experience stories** of how other young adults have tried to navigate certain topics in the Health Literacy Module. This would also provide a ‘point of difference’ to existing resources. So, we asked young people in our networks to provide a **short recording of their experiences** across the various topics in the module and the recordings were incorporated into the module.

Michelle

Through my input, the scope of the *Your health* module was broadened. I suggested including **sex, sexuality and gender identity** in the module. I also wanted to see the use of **empowering language** that reflects the whole person, not simply their diagnosis. I’ve got a 13-year-old girl who is a full-time wheelchair user and she wants to be a mum and she wants to have a boyfriend. There is no point in developing all this medical content in the *Your health* module, if it doesn’t support her to have a **good life**. Although the initial reaction felt a little awkward, the working group went on to include the topics in the module.

Reflection point

How do you expect your project will be enhanced by consumer involvement?

Promoting a sense of safety and support in the working group

Carolyn

Promoting wellbeing and a sense of safety was a **priority** for CP-Achieve Consumer Involvement practice. While all researchers were supported in thinking through how they could achieve this aim, there were **unique approaches**, as we can see in Jackie's example of developing a 'Working Together Agreement'.

Jackie

I recognised that parents might feel **vulnerable or overwhelmed** when talking about navigating healthcare services or advocating for their child, and that young people with cerebral palsy may feel **uncomfortable** due to their age or historical **power imbalances** experienced with clinicians. Working to foster a supportive environment meant:

- **collaboratively developing** a 'Working Together Agreement' during the first online working group meeting (see below) to offset any discomfort and balance any perceived power relations. I think that helped set the scene and made everyone a little bit more comfortable
- recognising that consumer research partners may need **time to build trust and confidence** to engage effectively
- fostering a **friendly environment** in online meetings, with no strict camera requirements and with gentle encouragement and invitations to speak, either in the chat or on audio/video.
- approaching discussions with parents with **empathy**, acknowledging their emotional investment in their child's wellbeing
- ensuring that **each person can speak** without putting individuals on the spot, and managing the louder voices in the chat or Zoom conversation
- providing **time** for people to think about materials and topics under discussion within meetings and **removing pressure** for immediate responses
- understanding the ways in which **medical and bureaucratic processes** can impact consumers' daily lives and allowing consumers to take breaks or reduce their level of involvement, where needed.

Michelle

Jackie provides a lot of **flexibility** to the consumer research partners in the working group. September was a tough month for me due to my daughter's surgery, and I lost track of everything. I missed a couple of meetings and felt guilty about it. I even considered stepping away. However, Jackie was understanding. She told me, 'That's OK. Come back when you're ready,' and expressed gratitude for everything I had done to date. Now that I'm back, she's so thankful and appreciative of whatever I can do.

Reflection point

What can you do to create a supportive environment that offsets any potential discomfort or power imbalance between researchers and consumers?

Our Working Together Agreement

- We will respect each other's opinions and experiences.
- We agree to acknowledge the different perspectives that we all bring to the table.
- Not all of us have lived experience. We will be mindful of this and be open to challenging/correcting the language we use.

> **"I've come to appreciate that sometimes pauses are good. They're not silent; they're not awkward pauses. Or maybe they are… But I've learnt that people are thinking, and I just give everyone some time."**

Jackie Ding, PhD Candidate

Promoting accessibility in the research project

Jackie

There were several steps I took to promote accessibility in the working group:

- I arranged meeting times to **suit the needs** of members.
- I recognised that everyone cannot make it to every meeting.
- I ensured those who were unable to make it to meetings had the option to **contribute outside the meeting** and were updated through meeting minutes.
- I provided flexible options to contribute during meetings: feedback in the chat function was an option if preferred to audio/video.
- I provided flexible **feedback options** on providing written material, such as by email or through individual communication, allowing people to go at their **own pace**.
- I ensured the language in the documentation was written in **Plain English** to be accessible to all working group members.

Michelle

Jackie was very **patient** on the calls. She gives you a lot of time to respond and to think. She's a very **good facilitator** of the conversation. She allows everyone to have their say and then draws in people who have not contributed as much. When you do speak, you feel heard. I definitely felt **cared for and nurtured** along the way.

Funding for consumer involvement

Carolyn

CP-Achieve researchers were often faced with organisation and planning challenges linked to approval timelines for grants and ethics processes, which had flow-on effects on consumer involvement. It was also common for researchers to initially **underestimate** the amount of time to put towards facilitating consumer involvement.

Jackie

Consumer involvement is an **investment** in better research processes and outcomes. To be successful, researchers need to allocate **additional time** to coordinate and support consumers, prepare accessible meeting materials, and build realistic consumer involvement plans and budgets into grant applications. I underestimated how much administration time I would need, particularly at the beginning of the working group. Some of the activities included creating Doodle polls to find a meeting timeslot that suited everybody, creating agendas in Plain English, following up after every meeting with minutes and ensuring everyone was logging their time to get paid.

Reflection point

What components of your project may affect your availability to support consumer involvement or the consumer involvement timeline? What can you do to manage risk?

> **“Working to manage timeframes and unexpected delays is critical for maintaining authentic consumer involvement.”**

Carolyn Pinto,
Consumer Coordinator

Table 14 highlights the time spent by consumer research partners and by the research team in supporting consumer involvement in this project, to provide some insight into **costs of involvement**. Funding for this project came from the University of Melbourne's Healthy Trajectories Seed Funding Round 2023.[33] Importantly, there is a significant difference in costs for advisory work (input into focus group discussions) and working group involvement. The working group members would be considered 'Equal Partners' in CP-Achieve's levels of consumer influence (see Table 12). Consumers were provided with gift cards valued at $40 for every hour worked.

For more information about payment of consumers, see 4. Funding for consumer involvement.

Table 14 Costs of consumer involvement in Jackie's research

Activity	Consumer involvement (including preparation time, meetings, materials development and document review)	Researcher time to prepare for and support consumer involvement (approximate)
Onboarding all consumers (document preparation)		**2 hours** (preparing induction slides, reading material, emails/ administration)
Consumer input into focus group discussions	2 partners x 3 hours + 1 hour per partner preparation = **8 total hours**	**1.5 hours** (induction meeting, post-meeting administration)
Consumer involvement in working group	3 partners x 1 hour working group meeting every fortnight for six months (13 meetings in total) + 30 minutes per consumer for preparation for each activity = **58.5 total hours**	Administration (agenda creation and distribution, meeting minutes write up) 2.5 hours per meeting x 13 meetings = **32.5 total hours**
Consumer review of health module	Involvement of 10 consumers between May and Dec: **94 total hours**	~5 hours per week administration
Total time	160.5 hours	101 hours
Total budget	$6,420	

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[33] Healthy Trajectories is a child and disability research hub located in The Royal Children's Hospital, Melbourne.

Challenges faced on the way

Carolyn

No process is without its challenges. Consumer involvement requires researchers to be highly **organised** and to be **flexible and responsive** to multiple ideas and approaches. It also supports the development of skills for **teamwork**, as discussed by both Jackie and Michelle below.

Jackie

Time was a big challenge for us, with everyone facing pressures. Offering **flexible options** for involvement helped us manage these constraints and accommodate medical appointments and other stressors. The time pressure actually made me more organised. Initially, the **large volume of feedback** from consumer research partners was overwhelming, but we managed it through **consensus-building** within the working group.

Michelle

We faced **time constraints** with both consumers and researchers feeling the pressure. Consumer research partners had to learn to keep **emotions** in check to influence the working group effectively. We also needed to **slow down** to accommodate members who required more time to respond. Some consumer research partners struggled with the **medicalised views of disability** from clinicians, feeling that these perspectives overlooked the character and individuality of people with disabilities.

Advice for researchers

Jackie

My biggest learning in this project is that things do take a lot longer than anticipated. Plan and budget for **extra time, manage expectations** and allow ongoing involvement after deadlines. Regularly check in with consumers to make sure they are satisfied with the research process. Check-ins build relationships of trust and help you address any environmental challenges to consumer involvement. **And finally,** don't expect to be an expert at the outset; look for ways to **improve your consumer involvement practice** and process as you go.

Michelle

I don't have advice for researchers per se except to think about the language you use. My daughter (who is a CP-Voice Advisor) would prefer to be called a consultant than a consumer – she feels it is more reflective of her influence. I know it's contentious, though, as everyone has a different idea. It's important to check in with your consumers and see what works for them.

Publications

Jackie is currently working on a manuscript exploring the collaborative process for this research.

> **“Don't expect to be an expert at the outset; look for ways to improve your consumer involvement practice and process as you go. I kept a reflective journal to track the consumer involvement process and consider ways I could iteratively improve it.”**

Jackie Ding,
PhD Candidate

Key takeaways

Conceptualising consumer involvement according to levels of influence can assist in planning consumer involvement.

Consumers can lead research or influence research as Consultants, Advisors and Equal Partners. In any given project, consumers can be involved at one or more of these levels.

The research cycle provides an invaluable reference point for identifying ways that consumers can be involved in research. Consumers can collaborate at the earliest stage of research in identifying research questions and priorities, all the way through to designing and implementing research, translating and sharing the findings, and deciding the priorities for the next research.

Chapter 8

Building authentic relationships: Consumer involvement in a scoping review

Follow this link

To hear researcher Dr Stacey Cleary and Consumer Research Partner, Freya Munzel talk about this project and how their working relationship developed.

Follow this link

To hear Sevastine Katsakis, CP-Achieve Consumer Coordinator, discuss ways to promote authentic involvement in your project.

Sevastine Katsakis,
Consumer Coordinator

> “Many researchers hesitate to engage with consumers, especially those with disabilities, fearing they might ‘get it wrong’ or ‘say the wrong thing’. In this section, researcher Dr Stacey Cleary and Consumer Research Partner Freya Munzel:
>
> - share their journey of collaborating on a scoping review
> - demystify the processes of relationship-building
> - describe what it might look like for a researcher and consumer research partner to work together.
>
> Before diving into their story, I’ll outline the project and explain how consumer coordinators supported both researchers and consumers in fostering meaningful relationships.”

Research project:

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

Researcher: Dr Stacey Cleary

Consumer Research Partner: Freya Munzel

About the project

The three-year scoping review, involving 12 researchers and three consumer research partners, looked at the participation experiences of young adults with cerebral palsy across key life areas. The initial idea for the research came from discussions between researchers and the CP-Unite Advisory Group[34] at the conception of CP-Achieve. The consumer research partners, including Freya, were recruited from CP-Achieve's Consumer Network as Equal Partners[35]. Stacey led the scoping review.

About Stacey and Freya

Dr Stacey Cleary is a physiotherapist and researcher and was a postdoctoral research fellow with CP-Achieve for the duration of this project. Freya is a young adult consumer research partner who brings her lived experience to her work with CP-Achieve. She has worked extensively in the disability sector, particularly with teenagers and young adults, creating and facilitating programs that encourage skill-building, connection and safe sharing of lived experiences.

Neither Stacey nor Freya had experience with consumer involvement or in conducting a scoping review before this project. Freya had started working as a consumer research partner on other CP-Achieve projects just before starting with this project.

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[34] A CP-Achieve advisory group of adults with cerebral palsy aged 18–30 years.

[35] 'Equal Partner' refers to the level of influence that the consumer has on the project. Equal Partners work with researchers on an equal basis to plan, undertake or disseminate the results of the research. For more information about other levels of influence, see Table 12 in 7. Involving consumers across the research cycle

Consumer coordinator support

Sevastine

Over the course of CP-Achieve, consumer coordinators supported researchers to build authentic relationships with consumer research partners by guiding them to **reflect** on their communication, **set expectations collaboratively, adapt** to consumers' needs, and **acknowledge** consumers' contributions. They facilitated effective matches between consumer research partners and researchers by understanding the interests of both parties, identifying common ground and providing briefings. The flowchart below (Figure 3) provides an example.

> **"Authentic relationships are built on trust, respect and open communication. They thrive when individuals act with integrity, show empathy, foster collaboration, acknowledge contributions and genuinely value diverse perspectives."**

Sevastine Katsakis, Consumer Coordinator

Figure 3 Steps to identify and involve consumers in CP-Achieve research projects

Researcher submits CP-Achieve's *Consumer Involvement Planning Guide and Budget Request form,* with support from the consumer coordinators and theme leader.

Consumers approached directly by consumer coordinator, or position is advertised. Where advertised, consumers submit Expression of Interest to consumer coordinator who reviews request in collaboration with the researcher.

Consumer involvement agreement signed.

Consumer coordinator prepares the consumer and researcher to meet each other, provides information about consumer's access needs to the research team.

Online/face-to-face introduction between consumer(s) and researcher, supported by consumer coordinator.

Researcher onboards consumer:

Negotiate supportive ways of working, consumer goals and interests

Discuss project goals, workplan and activities.

Consumer(s) collaborate in research activities and knowledge translation.

Consumer coordinators and mentors regularly check in and support consumers as needed.

Consumers are acknowledged commensurate with level of involvement (e.g. authorship, letters for resume).

Researchers close the loop:

Highlighting how consumer involvement has impacted the research design, planning, implementation and outcomes.

Sharing research results and implications in accessible format.

Consumer coordinator facilitates further project opportunities with the consumer.

Identifying consumers

Sevastine

The consumer coordinators worked with Stacey to identify consumer research partners with interests aligned to her project.

Stacey

Sevastine, one of CP-Achieve's consumer coordinators, worked with the research team to identify and onboard three consumers to collaborate on the scoping review. She drew upon our *Consumer Involvement Planning and Budget Application Form*[36] to inform potential consumers about the topic, expected commitment and timeframes.

James, Freya and Cassie, the consumer research partners involved in this project, were part of the Consumer Network and had *Consumer Profiles*[37] highlighting their research interests. Noticing a strong alignment between their profiles and the project, Sevastine reached out to gauge their interest. After a face-to-face meeting, all three were enthusiastic about joining the research team, and the budget allowed for all three to be involved. I had hoped to include three consumer research partners for a greater diversity of experience and with the expectation that at least two participants would be available at a time if one could not participate in an activity or meeting.

Good practice

CP-Achieve recommends a minimum of two consumer research partners per project, to offset potential power imbalance and provide peer support.

Reflection point

What can you do to find consumers who have interests aligned to your project?

Getting started

Sevastine

Stacey and Freya have demonstrated that collaboration approached with openness and curiosity can foster trust and confidence between researchers and consumers.

Stacey

Sevastine briefed me on the consumer research partners prior to meeting them, providing insight into their preferences, support needs and interests. I met with the consumer research partners several times to discuss their preferred involvement in the research process. Around the same time, I met with the CP-Achieve researchers on this project (a team of 12 people) about the scoping review methodology. I offered the consumer research partners the option to join those meetings or meet separately with me for updates and discussion. They preferred the latter, so I served as a bridge between the two groups, sharing relevant discussions with both.

Freya

I was pretty nervous when we first met. I remember Stacey asking lots of questions on how she could best support me. I could tell she was nervous as well. At the start, it was difficult for us consumer research partners to understand how the research process worked. Sometimes it was hard for Stacey to explain, particularly when she was in a time crunch. Over time we were able to share that we needed more time to consider things. Now there is less time pressure, and we have a more meaningful say. It has become easier as we have all developed skills in working together as well as just getting used to how the research process works.

Key learning

It is not uncommon for consumer research partners and researchers to take some time to navigate their roles and develop confidence in working together. Research processes and methods are often new to consumers, and researchers are learning the skills and knowledge to develop and sustain new relationships. Consumer research partners may also be unaccustomed to having their lived experience so highly valued. Our experience is that consumer research partners and researchers develop confidence and skills by 'doing', by getting started and engaging in the research collaboration.

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[36] For a working example of this form, go to 11. Getting started: Steps for your journey.

[37] Ibid

Maintaining regular communication

Sevastine

Regular check-ins, even through informal instant messaging platforms, help maintain momentum, foster engagement and strengthen connections. Stacey proactively bridged communication gaps by adopting a flexible approach to meet consumers' needs, enhancing interactions over time.

Stacey

We had a mix of fortnightly and monthly meetings at peak points of the research cycle, with gaps at low points due to the research stage, my part-time working status and other responsibilities (such as grant writing). Recognising that the gaps, although at times unavoidable, were unhelpful for maintaining momentum, I started an instant messaging group to stay in touch. Using the messaging platform, I could keep the consumer research partners abreast of my activities and timelines, and build and maintain our relationships. The team preferred the instant messaging group over email for smaller tasks or quick questions. This really improved our relationships.

Freya

There were times when we wouldn't hear from Stacey for a while, particularly at the beginning. The communication side of things has improved drastically with a greater understanding of our needs.

> **"The instant messaging group helped keep consumer research partners engaged and on top of the project's progress. It is a little less intense than email, and we could just do a pretty low-key, regular check-in."**

Dr Stacey Cleary, Postdoctoral Research Fellow

Key learning

One of the most common challenges in CP-Achieve was to sustain communication between researchers and consumers through lulls in research activity. Collaboratively developing communication strategies with consumers can ensure continued and effective involvement of consumers.

Reflection point

How can you involve consumer research partners in identifying ways to keep in touch, particularly between research activities and meetings?

Accommodating consumer preferences

Sevastine

Stacey's efforts to tailor communication, create flexible processes and address potential power imbalances exemplify the principles of authentic relationships. Freya's appreciation of the adjustments Stacey made highlights how these changes improved collaboration and reduced barriers, making it easier for everyone to contribute and work together effectively.

Stacey

Sevastine helped me understand the different preferences each consumer research partner might have when working with the research team. Over time, I built on this knowledge, adjusting my approach based on what worked best for each consumer research partner. Initially, I sent documents for review by email, but I soon realised it was more effective to discuss the content during meetings. The team preferred to review documents together rather than individually, so I began sending documents out ahead of a meeting time to help the team prepare. I made sure the Zoom meetings were scheduled at convenient times for the consumer research partners. During meetings, I would explain the content in lay terms. We ended up extending meeting times as we realised we just needed more time to talk! I also offered a variety of options for communication and encouraged consumer research partners to share their preferences via text or email if they didn't feel comfortable expressing them in meetings. I tried to create an environment that minimised any perceived power imbalance, though it was a challenge to know if I was truly getting it right.

Freya

Stacey has been really good at accommodating our needs because she recognises that everyone works differently. For example, I struggle with notetaking, so she asks, 'Do you want me to take notes, or what points do you want me to write down?' Some of us (consumer research partners) prefer having information sent by email, while others prefer reminders via text message. Having multiple ways to receive notifications has been really helpful. She also highlights specific sections of documents that are most relevant to our expertise, making it easier to prioritise what to work on. Recently, she introduced a timesheet to track our work, which has been incredibly helpful. Instead of emailing her every time I do work, I now send the timesheet at the end of the month, which benefits both of us.

Reflection point

How can you work with consumers to identify and accommodate their preferences and needs?

> **"Working with CP-Achieve has shown me that with appropriate support and the right disability accommodations, I can produce valuable work without becoming tired or stressed. When you have the right support, you realise you can do it."**

Freya Munzel, Consumer Research Partner, young adult with cerebral palsy

Working together

Sevastine

Stacey fostered a dynamic and inclusive environment, involving consumer research partners across the research cycle, seeking their feedback and recognising their unique insights. This ensured the project was shaped by those with relevant expertise and lived experiences.

Stacey

Freya, James and Cassie were active in all stages of the research cycle, as you can see in Table 15. We coded the data from the scoping review thematically and involved the consumer research partners in analysing the key themes and their relationship to each other. Each time I presented the data, they would ask questions like, 'Did (a topic they felt was important) come up?' and 'Is that theme actually related to this other theme?'. They would also point out areas where I had separated topics, but they really needed to be combined with others. I also checked in to ensure that the way I interpreted data made sense from their lived experience.

One example is when we were talking about developing confidence as a subtheme of the theme 'Getting to know myself as an adult'. I presented the main ideas in a mind map for discussion with Freya, James and Cassie. They suggested I review the results on discrimination and time availability/use and how these factors contributed to developing confidence, skills, choice and control for people with cerebral palsy as they become adults. They also highlighted the need to review the literature on the added load faced by people with cerebral palsy in terms of administering supports and purchasing and managing equipment. I captured these ideas in a different colour on the map so I could follow up.

Reflection point

How will you ensure that you accurately capture and reflect the ideas and priorities of consumers in your research?

Freya

Stacey always shared everything with us, but she would also ask us to comment on specific aspects, recognising that our lived experience would give us specific insights. She would say, 'You're better placed to comment on this than I am'. It was really good that she recognised this. For James and I, we've had a lot of say on different things and really influenced this project.

Pictured: The social media tile used to promote a webinar, where James co-presented with Stacey.

My CP Guide presents

Doing the important things of life: Understanding the participation of young adults with cerebral palsy

Webinar at 2pm (AEST)
Wednesday, 22 May 2024

Register for free ›

Christine Imms, Prue Morgan, Stacey Cleary, Andrew Pope, and James Plummer

Table 15 Consumer involvement across the research cycle in Stacey's scoping review

Stage in the research cycle	Research activity	Consumer role
What to research	Determining research priorities for CP-Achieve	CP-Unite[38] advised of the need for more information about the key life areas young adults with cerebral palsy wanted to participate in and how this participation could be optimised.
Designing the study	Determining the scope of the study	Stacey developed the methods of the study with other academic researchers based on advice from CP-Unite regarding the 'key life areas' to explore.
Implementing the study	Analysis of results	Meetings with Stacey, Freya, James and Cassie made sense of, organised and interpreted data from the scoping review, highlighting the findings' gaps, relevance and meaning.
Sharing results	Sharing findings through conferences and events	Freya, James and Cassie co-authored the published journal article. James presented study results through a webinar hosted by My CP Guide[39]. Freya presented study results through a pre-recorded video for the Australasian Academy of Cerebral Palsy and Developmental Medicine[40] (AusACPDM) conference in 2024.
What to do next	Developing grants for future research	Freya, James and Cassie collaborated with Stacey on two grant proposals to fund studies that address recommendations from the findings of the scoping review. Both applications were successful, and the team is now working together to design a series of participation-focused modules that aim to support young people with cerebral palsy to increase their knowledge and skill in important life areas of young adulthood.

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[38] CP-Unite is CP-Achieve's advisory group of young adults with cerebral palsy aged 18–30 years.

[39] *My CP Guide* collects, reviews and assesses existing, credible information about cerebral palsy from around the world and makes it readily available for people with cerebral palsy and their families.

[40] The Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) aims to provide multidisciplinary scientific education for health professionals and promote excellence in research and best-practice clinical care for children and adults with cerebral palsy and developmental conditions.

Research impact

Sevastine

Freya and James drew from their lived experience to shape the recommendations from the scoping review, which were included in a journal article. They were also pivotal in responding to the comments made by the reviewers as part of having the journal article accepted for publication.

Stacey

In the final paper, we included recommendations for policymakers and future research, and the consumer research partners helped develop and finesse those recommendations. Then we went through different versions of the draft that I'd written, and they had recommendations about words and phrases to change. I think it's been a really beautiful collaboration.

Freya

James and I, we've had a lot of say on different things. For example, the peer review of our scoping review journal article came back with comments, and James and I formulated a response to one of the questions based on our lived experience. The suggestion from the peer reviewer was to reduce the impact of negative social attitudes on people with cerebral palsy by providing them with coaching on how to manage these. Our perspective was that while it might be useful in the short term, it doesn't solve the issue in the long term of society having bad attitudes towards disabled people. We don't think we should be focusing on trying to build people with cerebral palsy's resilience and ability to deal with ableism. We are trying to change the system itself.

Funding for consumer involvement

Sevastine

Table 16 highlights the time and dollar investment of both Stacey and the consumer research partners to facilitate consumer involvement in this project. Consumer work was paid with gift cards valued at $40 per hour.

Table 16 Consumer involvement in Stacey's scoping review

Activity	Consumer involvement (including preparation time, meetings, materials development and document review)	Researcher time to prepare for and support consumer involvement (approximate)
Onboarding consumer research partners	2 hours x 3 consumer research partners = **6 hours.**	**8 hours** (writing position description, preparing induction slides, reading material, liaising with consumer coordinators, emails/ administration) **5 hours** (induction meeting, post-meeting administration)
Meetings with consumer research partners throughout the project	3 partners x 12 working group meetings (2 hours) + 30 minutes preparation for each activity = **90 total hours**	Administration (agenda creation, put together content for review, distribution, meeting minutes write up) 1.5 hours per meeting x 12 meetings (18 total hours preparation) + meeting time (24 hours) = **42 total hours**
Preparing for joint presentations	1 hour webinar = **9 hours preparation** 5 minute pre-recorded segment = **5 hours preparation**	1 hour webinar = approximately **14 hours of support** 5 minute segment = approximately **3 hours of support**
Total time	110 hours	72 hours
Total cost	$4,400	NA

> Involvement in this project has not been tokenistic. Genuinely being involved and influencing this work has given me a lot of confidence in my skills and abilities and the fact that they are valuable and useful.

Freya Munzel, Consumer Research Partner, young adult with cerebral palsy

Recognising and valuing consumer contributions

Sevastine

Stacey's efforts to ensure consumer research partners were included as authors highlight her commitment to authentic consumer involvement. Freya's perspective underscores the importance of the consumer research partners' involvement in strengthening the research.

Stacey

When it came time to publish, I was committed to ensuring that the consumer research partners were included as individually listed authors on the journal article (i.e. not as 'CP-Achieve Research Group'). At the point of initial submission, only 10 authors could be listed individually with the journal. I asked the journal whether they would consider featuring the full 15 authors if the manuscript was accepted, and in the meantime, I talked with the team about the situation and the importance of including the consumer research partners as named authors.

I made sure that Freya, James and Cassie were in that top 10 author list, just in case the request to list all authors individually wasn't granted. I found it quite stressful; I really didn't want to let Freya, Cassie or James down or anyone else, for that matter. Fortunately, the journal agreed to list all authors individually, recognising the work of all team members.

Freya

It's really important to recognise the value that people with lived experience bring to research and that it can make research much stronger and more relevant. It is not just a pat ourselves on the back style tokenistic gesture. It is a useful and important part of the research process.

Reflection point

What are some of the ways that you could involve and recognise consumers in your project?

What barriers might you face in involving and recognising consumers, and how can you address these?

How can you celebrate and share how consumers are involved in your project?

The consumer-researcher relationship

Sevastine

Authentic relationships in research are built on mutual respect, trust and a balance of professional and personal connections. Stacey and Freya developed genuine rapport while maintaining the integrity of the research process.

Stacey

I really like James, Freya and Cassie. It is fun to meet with them, and I enjoy working with them. They tease me sometimes for being a nerd. James says, 'Stacey, you bring the research and we bring the life'. I've had to learn how to balance emerging friendships with professional boundaries and respond to my duty of care when needed. Because we got along well, when funding opportunities were popping up, I was like, 'Oh, do you want to be a part of this with me?' or 'Do you want to try doing this together?' We applied for two grants and were successful.

Freya

I've discovered that Stacey is a lovely person. We have a lot of fun working together. We've started meeting face-to-face, booking a meeting room in the library to work. I've greatly enjoyed working in person. It is work, but we get along well as a group.

Reflection point

How do you intend to build and sustain relationships with consumers on your project?

Pictured: From left to right, Freya, Georgie Rose[41], Cassie, Sevastine and Stacey (front) sit together discussing International Day of Persons with Disability in Murdoch Children's Research Institute in 2024.

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[41] Georgie Rose is Research Operations Manager at University of Melbourne's Healthy Trajectories, a child and disability research hub located in the Royal Children's Hospital Melbourne, Australia.

Benefits of consumer involvement

Sevastine

Through their collaboration, Stacey and Freya experienced growth and empowerment. The involvement of consumer research partners not only enriched the research process but also fostered new confidence and opportunities for everyone involved.

Stacey

I feel much more confident in the research outcomes and my role in producing this work because I wasn't trying to interpret data without lived experience. They were there to help with that and that's their expertise. It's a very good piece of work and it wouldn't be the piece of work that it is without Freya, James and Cassie.

Freya

A key benefit of CP-Achieve was my increased confidence in my own capacity to work and in the value of my work. I have learnt what accommodations I need to work most effectively, and this has made it easier for me when I am working with a new researcher. This has led to new work opportunities as a Lived Experience Tutor teaching a subject on disability to medical students, alongside a medical tutor. A lot of the skills I learnt and developed through CP-Achieve empowered me to be able to get the job and do the work.

My biggest highlight was watching Stacey's presentation at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, which included a video I had prepared. On the same day, I got my new job as Lived Experience Tutor at the University of Melbourne, where Stacey had been my referee.

> **“It's a very good piece of work and it wouldn't be the piece of work that it is without Freya, James and Cassie.”**

Dr Stacey Cleary, Postdoctoral Research Fellow

Advice for researchers

Sevastine

The importance of building rapport, understanding individual preferences, and maintaining flexibility in communication when working with consumer research partners is key to the advice provided by Stacey and Freya.

Stacey

It's extremely important to be organised. It can be a real challenge to balance the need to create content and get the work done, along with other work responsibilities and life challenges, and the need to be organised enough to send content to consumer research partners in advance with enough notice before meetings. But this is important. Stay in touch using communication approaches that work for your consumer partners. Learn about your consumer research partners' preferences as you go and respond to these by adjusting your practice. Don't forget to enjoy yourself on the way.

Freya

It is vitally important to build rapport with the people you work with and acknowledge that everyone is going to have different preferences for working, and they may not fully know those when they start. So even if they say, 'I'll respond over email', over time, they may realise it's not working for them, so it's really important to just keep checking in and saying 'Is this working for you?' Ask, 'Would you like me to meet over Zoom as well to go over your responses?' Check in regularly, knowing that the consumer may also be exploring what works for them, and give them time to do so.

Publications

Cleary, S. L., Morgan, P. E., Wallen, M., Honan, I., Shields, N., Munzel, F. E., Plummer, J. R., Assaad, C., Karlsson, P., Culnane, E., Ding, J. Y., Holmes, C., Dutia, I. M., Reddihough, D. S., & Imms, C. (2024). Experiences of participation in daily life of adolescents and young adults with cerebral palsy: A scoping review. Developmental Medicine & Child Neurology, Advance online publication. https://doi.org/10.1111/dmcn.16196

Plain language summary: https://doi.org/10.1111/dmcn.16228

Webinar involving Stacey and consumer research partner, James: https://www.mycpguide.org.au/info-resources/independence-and-inclusion/webinar-doing-the-important-things-of-life-understanding-the-participation-of-young-adults-with-cerebral-palsy?searchQuery=webinar&pageNumber=1

Key takeaways

Building and sustaining relationships between consumers and researchers is a cornerstone of authentic involvement.

Negotiating ways of working together and checking in to make sure these are meeting everyone's needs are two ways of creating respectful and responsive working relationships.

Maintaining regular and ongoing communication, even during periods of lower research activity, is respectful and promotes engagement.

Involving two and preferably more consumers promotes authentic involvement and provides opportunities for peer support, diversity of experience and likelihood of consumer involvement during all research activities.

Chapter 9

Working with young adults who use augmentative and alternative communication: Involvement in a mixed-method and qualitative study

> “
>
> People who use augmentative and alternative communication (AAC) are often excluded from research that impacts their lives. In this section, I provide background on One Group Our Voice, an advisory group created to seek perspectives from AAC users, and Jacinta Pennacchia describes CP-Achieve research involving AAC users. Both examples provide insights into:
>
> - communication approaches
> - accessibility needs
> - budgeting
> - benefits of involving consumers who use AAC.
>
> ”

Sevastine Katsakis,
Consumer Coordinator

Research project:

Assessing mental health in young people with complex communication needs.

Researcher: Jacinta Pennacchia

About the project

Jacinta Pennacchia's PhD research with CP-Achieve consisted of three interconnected studies: a systematic review of mental health in people with complex communication needs; a mixed-method study exploring workforce perspectives on assessing the mental health of AAC users; and a qualitative study exploring AAC users' views on wellbeing and mental health assessment processes.

About Jacinta

Jacinta Pennacchia is a speech pathologist completing her PhD at the University of Melbourne. She has experience working with people with complex communication needs but had little experience with consumer involvement in research prior to joining CP-Achieve.

Follow this link

To hear Sevastine Katsakis, CP-Achieve Consumer Coordinator, talk about involving consumers who use AAC in research.

Identifying consumer research partners

Sevastine

We, as consumer coordinators, supported Jacinta in designing a presentation of her research to pitch for consumer research partner involvement. We promoted her presentation through our networks, and Shirls, a member of One Group Our Voice,[42] Greg, a member of CP-Unite,[43] and Chris, a member of the Parent Advisory Group,[44] expressed interest.[45]

Jacinta

I worked with three consumer research partners during this research, two of whom have communication access needs. Sevastine helped me develop a short online presentation of my research topic, including a **call for consumer research partners**. We invited young adults with cerebral palsy who use AAC and parents of AAC users to attend. Three individuals – two young adults with cerebral palsy who have communication access needs (Shirls and Greg) and one parent of a young AAC user (Chris) – joined the project and have been involved since.

Working with AAC users

Sevastine

AAC describes the range of ways that a person communicates besides talking. Augmentative communication involves using strategies to add to someone's speech and alternative communication describes methods used instead of speech. Each AAC user employs a **unique combination** of AAC strategies to communicate.

Each AAC user has unique **communication preferences and needs**. Start by understanding these preferences and needs so that communications and meetings can accommodate these to optimise involvement. We recommend that you collaboratively agree on **AAC etiquette** at the outset of any project. Some suggestions to get started, are described in the box below.

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[42] A CP-Achieve advisory group of adults with cerebral palsy who use AAC (augmentative and alternative communication).

[43] A CP-Achieve advisory group of adults with cerebral palsy aged 18–30 years.

[44] A CP-Achieve advisory group of parents who have a young person with cerebral palsy.

[45] For information on the different CP-Achieve Advisory groups, go to 2. Consumer Involvement in CP-Achieve

AAC etiquette

In CP-Achieve's Inclusive Research Toolkit,[46] co-authored by AAC users, the following AAC etiquette is recommended:

1. Address an AAC user directly, maintain eye contact and engagement. Don't look at their device unless needed.
2. Ensure that AAC users have adequate and equitable opportunity to speak.
    - AAC users are likely to take extra time to generate a message or response and may take more time to understand or process a question or comment. Find out how to know that an AAC user is generating a response, especially if communicating over videoconference.
    - Watch for whether an AAC user is generating a response.
    - Maintain silence while a message or response is being generated. Be comfortable with silence, don't try to fill the silence. Don't interrupt.
    - Leave plenty of time in meetings for the time taken for AAC users to generate their messages or responses.
    - Make sure that individuals who communicate more quickly do not dominate a conversation or meeting.
3. Provide meeting or research materials in advance to assist AAC users to prepare their thoughts, queries and responses on devices.
4. Know how AAC users wish to work with support workers. AAC users will have preferences about how and when they need support and whether and under what circumstances they are willing for a support worker to speak, translate or re-voice for them.
5. Transparently negotiate the etiquette as part of establishing research partnerships with individuals or advisory groups.

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[46] Walsh, M., Harman, I., Manning, P., Ponza, B., Wong, S., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024). Inclusive research toolkit – including people who use augmentative and alternative communication (AAC) in research. https://acu.qualtrics.com/jfe/form/SV_3aU481INyYDhaZg

Jacinta

Consumer research partners involved in this research used a range of AAC strategies, including speech, speech-generating devices and body language.

Prior to this research, I had experience working with AAC users as a speech pathologist, which helped me feel confident when starting out. But working with AAC users is not as hard as you think. People who use AAC know they use different communication strategies – it's not a secret, so just ask them, 'How can I be a good communication partner?'

> **"People are often scared of getting it wrong when communicating with AAC users and it holds them back. We read other people all the time, whether they use communication devices or not, and adjust our own communication accordingly. It is the same thing. We don't need to make it more complicated than that."**

Jacinta Pennacchia, PhD Candidate

Consumer influence throughout the research cycle

Sevastine

Here in Jacinta's study, we see AAC users (and a parent) embedded within a research project, undertaking a range of critical roles across the research cycle, significantly **influencing** both the research process and outcomes.

Jacinta

Shirls, Greg and Chris were involved **from the beginning** of the first study, with the most significant influence in the second and third studies. In the first study, the focus was on keeping consumer research partners informed about findings from the systematic review. In the second and third studies, they were directly involved in determining the study scope, designing and implementing the studies, and sharing results. Table 17 outlines their involvement.

Table 17 Activities and influence of consumer research partners

Stage in the Research cycle	Research activity	Consumer role
What to research	Determining the scope	Greg, Shirls and Chris influenced the scope of the research, ensuring mental health problems and positive mental health were both prioritised.
Designing the studies	Participant selection	In the second study, Greg, Shirls and Chris broadened the range of occupations that would be approached as a source of potential participants.
	Interview questions	In the second and third study, Greg, Shirls and Chris contributed to the interview questions. In study three, Greg and Shirls helped design data collection practices.
Implementing the studies	Recruiting participants	Shirls developed a flyer advertising for participants for study 2. Shirls and Chris appeared in a video to promote the participation of AAC users in study 3. The video is available on Jacinta's LinkedIn profile.[47] They also supported the recruitment process by emailing organisations to be involved in the study or suggesting organisations for Jacinta to contact.
	Conducting interviews	Greg attended Good Clinical Practice training so that he could co-facilitate interviews in study 3. The intention was to offset the power imbalance between the researcher and AAC users who were study participants.
	Analysing results	Shirls, Greg and Chris analysed results and influenced key themes and findings in studies 2 and 3.
Sharing results	Co-authors on journal articles, conference presentations and CP-Achieve webinars	Shirls, Greg and Chris are co-authors on journal articles developed for the second and third studies. They were also involved in presentations (e.g. CP-Achieve webinars[48]).

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[47] https://tinyurl.com/5c5b7tvy

[48] Greg, Shirls, and Chris were involved in Jacinta's webinar: Assessing mental health in young people with CCN: Project update and consumer perspectives, available online at https://www.youtube.com/watch?v=SexewcSMPJs

One Group Our Voice: How AAC user involvement in CP-Achieve research began

The beginning

Recognising the underrepresentation of young adults with complex communication needs in health and disability research, CP-Achieve established a consumer advisory group, 'One Group, Our Voice,'[49] to provide advice on involving AAC users as consumer research partners and research participants.

One Group Our Voice consisted of four members who use AAC. Members met every three weeks over a couple of years to work on group projects and collaborate with researchers and students seeking advice on working with AAC users.

The group was facilitated by a speech pathologist completing a PhD with CP-Achieve who had a specific interest and expertise in collaborating with AAC users. She communicated with members before meetings, developed accessible meeting materials, supported consumers in accessing and responding to content, facilitated meetings and shared meeting minutes. Family or paid support workers attended meetings to assist with communication and technology and worked with One Group Our Voice members between meetings to prepare for sessions or complete research activities. The researcher also coordinated the involvement of support workers.

Resource development

One Group Our Voice has been instrumental in creating resources to support researchers involving AAC users as participants and consumer research partners, and in demonstrating the **feasibility and benefits** of engaging AAC users as research partners.

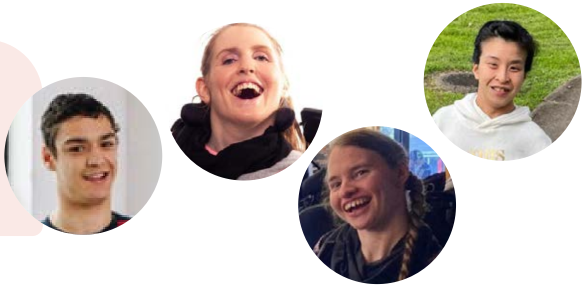
The Inclusive Research Toolkit and accompanying journal article provide a framework for researchers to involve AAC users in research. Click this link or scan the QR code to download a copy of the Toolkit.

Research impact

In addition to creating the Toolkit, One Group Our Voice has also:

- provided feedback on research design and implementation to facilitate the involvement of AAC users in CP-Achieve research
- delivered national and international presentations sharing the knowledge they have generated. Watch their webinar on Hearing our voices: Perspectives from CP-Achieve's advisory group of AAC users here[50]
- achieved recognition. One member, Brenton Ponza, won the 2024 Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Award for Outstanding Contribution - Person with Lived Experience
- co-authored a journal article that includes a framework for involving people who use AAC as research participants and consumer research partners, entitled Including people who use augmentative and alternative communication in qualitative research: Can you hear us?[51] This accompanies the Inclusive Research Toolkit outlined earlier.

Pictured: One Group Our Voice members Brenton, Brodie, Penny and Shirls



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[49] Funded by the CP-Achieve small grants program and the State Trustees Australia Foundation Community Inclusion grant.

[50] https://www.youtube.com/watch?v=MMVkBIgbQ-k

[51] https://doi.org/10.1177/16094069241234190

> “Jacinta gave me time to give my thoughts and didn’t discuss me with people outside of the group. We brainstormed and discussed mental health, which is an important topic.”

Shirls, Consumer Research Partner, AAC user

Promoting a sense of safety and support

Sevastine

As outlined in CP-Achieve’s Inclusive Research Toolkit, AAC users and their families can face **ableism, paternalism and medical trauma**, often related to failure to seek their consent, or their consent being ignored or overridden. They can also face social isolation and reduced social participation, so **managing power** in the research relationship and **creating a sense of safety** and support are very important.

Jacinta

A key approach to fostering a safe working relationship was **removing hierarchies** based on professional experience from our interactions. I consciously avoided acting as a speech pathologist during meetings to prevent an imbalanced **power dynamic**. For example, I never asked Shirls about her type of communication device and refrained from using technical terms related to communication or speech. If something wasn’t clear, I simply asked, ‘Can you say that again?’

I also shared my **personal reasons** for studying mental health, which helped to create an open and supportive environment – we had a **common interest**.

Developing a video to showcase consumer roles

Sevastine

Several consumer research partners videorecorded their contributions for conferences and CP-Achieve webinars. Jacinta provides an example.

Jacinta

We decided to make a video exploring the consumer research partners’ roles and experiences in our project. The video was edited into shorter clips for webinars, social media and promotions. Greg preferred using text bubbles over appearing on camera, which I supported, as it’s important to respect how consumer research partners want their information presented.

Follow this link

To view an example of how the clips were used.

Funding for consumer involvement

Sevastine

Jacinta's project was funded by external funding, and consumers were paid using a gift card system similar to that provided by CP-Achieve. The rate for consumer involvement was based on Victorian Comprehensive Cancer Centre (VCCC) Alliance cost model and changed from $40 to $45 over the period of the research.[52]

Jacinta

I received funding for consumer involvement from two external organisations, AGOSCI[53] and Speech Pathology Australia.[54]

Activities I budgeted for included onboarding, Good Clinical Practice training, meeting preparation (reading agenda, programming responses in AAC), the meeting itself, actioning tasks post-meeting and more. Onboarding involved an orientation to the research and the AAC user introducing themselves and their communication needs.

Cost examples from the project:

- Typically, meetings with Shirls and Greg took 1 hour 45 minutes each. Meetings with Chris were 45 minutes long.
- For consumer representation at conferences (1 hour each), I would need 8 hours for preparation, editing and face-to-face time.
- For our recruitment videos, we required 1 hour each for 3 consumers + 5 hours of editing time for the researcher.

Benefits of consumer involvement

Sevastine

Involving AAC users and parents of AAC users is critical to redress their exclusion from research that directly affects them.

Jacinta

Consumer involvement leads to more relevant research – it keeps you on track, researching topics of importance to consumers. It also improves research design and boosts academic engagement, especially when consumer research partners co-present. Consumer involvement kept me motivated. Sometimes academia is very intense, and having chats with consumer research partners is really reassuring; it makes you feel good.

Challenges along the way

Sevastine

CP-Achieve researchers commonly faced challenges in keeping in touch with consumer research partners. Jacinta explores this further.

Jacinta

As a PhD student, I was learning research methods myself, so sometimes consumer research partners were involved to a lesser extent than we hoped because I was prioritising my own learning of complex ideas.

I also faced challenges staying connected with consumer research partners during periods of low involvement. My supervisor suggested I be upfront and acknowledge the disconnect, which quickly helped re-establish communication.

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[52] This cost model is available at: https://vcccalliance.org.au/consumer-engagement/resources/consumer-cost-model/

[53] AGOSCI is an Australian organisation that aims to provide a community and platform for multimodal communicators, their families and supporters, and the professionals who work with them; to facilitate opportunities and activities that work in service of AGOSCI's vision; and advocate for their community.

[54] Speech Pathology Australia is the national peak body for the speech pathology profession in Australia.

Impacts of consumer involvement

Jacinta

At the beginning of the project, the consumer research partners were involved in discussions about mental health and its importance to AAC users. We explored the differences between positive mental health and mental health problems. Consumers reiterated that both aspects are important and that my research should encompass both.

In the mixed-methods study (study 2), there was a lot of discussion about who the workforce participants would be. It was really helpful to have that chat with consumer research partners because they thought of occupations that I hadn't really thought would be involved. This helped with recruitment because we shared the survey with a wider range of disciplines across different organisations.

In the third study, I was initially concerned about whether AAC user participants would complete the research themselves, or whether a support person might complete it on their behalf. This was a concern for me because I wanted to gather AAC users' perspectives. Greg and Shirls pointed out that you never really know who is completing an online survey or an email interview, regardless of whether they are AAC users. That was such an interesting way to think about it. I realised I shouldn't make AAC users work harder to participate than anybody else.

Advice for researchers

Jacinta

You don't need to skirt around AAC users. Instead of letting discomfort get in the way, just ask them, 'How can I be a good communication partner?' and tell them, 'If I'm doing anything wrong, let me know'. And then just try; it is really not as hard as you think.

It's important not to be tokenistic. Shirls, Greg and Chris were only included as authors in journal articles because they genuinely contributed. I was really upfront, explaining the guidelines for authorship and why they would be authors on some papers and not others. This is really important for authentic consumer involvement.

Good practice

Explain authorship guidelines to consumer research partners upfront.

> **"Involving consumer research partners that use AAC is a lot of fun. You'll learn a lot from the group."**

Shirls, Consumer Research Partner, AAC user

Key takeaways

Involvement in research is a human right; however, people with complex communication needs (and AAC users, more specifically) are frequently excluded from being consumer research partners and participants. Consequently, their perspectives do not inform research and their needs are not researched.

Researchers who rise to the challenge of authentically involving AAC users in research will see enormous benefits.

AAC etiquette should be explored and agreed upon at the project outset to create a safe and effective work environment.

Time is crucial for accessibility: allocate more time than usual for preparation and meetings. Schedule separate meetings, if needed and ensure ample time during conversations for interactions and responses with AAC users.

Working with AAC users has additional costs, which need to be budgeted appropriately.

An Inclusive Research Toolkit is available to guide researchers to develop and implement accessible research materials for research participants and consumer research participants who use AAC.

Publications

Webinar: Assessing mental health in young people with complex communication needs: project update and consumer perspectives. Available online: https://www.youtube.com/watch?app=desktop&v=SexewcSMPJs&t=1s

Chapter 10

Building confidence: Consumer involvement in a systematic review, and qualitative and feasibility studies

James Czencz, PhD Candidate

> “Researchers can often feel overwhelmed by consumer involvement practices and be unsure of where to begin. In this section, Gaurav Thakkar and I share our journeys - starting small, learning along the way and gradually building confidence in consumer involvement. We'll share how:
>
> - consumers were identified for the project
> - the value of consumer involvement became clear
> - we travelled together
> - consumer involvement was funded
> - we experienced the benefits and impacts.”

Research project:

Evaluating physical activity interventions to improve participation and wellbeing for adults with complex cerebral palsy

Researcher: James Czencz

Consumer Research Partner: Gaurav Thakkar

About the project

The research explores how clinicians can improve the quality of life and participation of adults with cerebral palsy, particularly those with more complex presentations, through physical activity and exercise. It comprises three studies, undertaken over five years: a systematic review of literature on physical exercise for adults with cerebral palsy; a qualitative study examining the wants and needs of adults with cerebral palsy who use wheelchairs to engage in community-based physical activity; and a feasibility study testing peer-mentored, gym-based exercise interventions for an adult with complex cerebral palsy.

About James and Gaurav

James Czencz is a physiotherapist and PhD candidate at the Australian Catholic University. Gaurav Thakkar, a Consumer Research Partner with lived experience of cerebral palsy, was involved as an adviser in CP-Unite and in several of CP-Achieve's individual research projects. Before CP-Achieve, neither James nor Gaurav had experience with consumer involvement in research.

Follow this link

To hear PhD Candidate James Czencz, and Consumer Research Partner, Gaurav Thakkar, talk about developing confidence in consumer involvement and working together.

Getting started

James

At the outset of the project, I remember speaking to Margaret (CP-Achieve's Consumer Involvement Theme Leader) about being **nervous** that I might **say the wrong thing or do the wrong thing** to consumer research partners. It can be daunting to observe complex consumer involvement practices. I'm here to tell you that it doesn't have to be that complicated; you can start with just a coffee and chat.

During my systematic review, I approached Ann, a physiotherapist who is also a parent of an adult with cerebral palsy. As a physiotherapy student, I had previously supported her during hydrotherapy sessions with her son. Our previous working relationship was in some ways like consumer engagement; she was able to explain the value of hydrotherapy and exercise for her son before I even had a project.

Ann was very much a **sounding board** for me during my systematic review. She really pushed me to think from the **consumer perspective**. In response to my plans to do a gym intervention as part of my PhD she said, *'I'm happy to bring my son to your gym intervention, but it needs to be for a purpose. He needs to be benefiting from this intervention.'* I'll always remember that comment as something you wouldn't automatically consider unless you either have cerebral palsy or are close to someone with cerebral palsy.

As I moved into the qualitative phase of my PhD, I knew the project would benefit from more consumers' perspectives. I approached Wendy, who has cerebral palsy and had been a previous client, to become a consumer research partner. I also approached CP-Achieve, which led to Gaurav joining the team. I worked with these three consumers for three years, and then in 2024, Cassie joined our consumer team, approaching me after hearing about our project in a CP-Achieve webinar I hosted. I also consulted with CP-Achieve's advisory group of young adults who use augmentative and alternative communication (AAC), One Group, Our Voice.

Gaurav

When I joined CP-Achieve, I wasn't sure how I could contribute or what my role would be. I was introduced to the program after finishing Year 12 and transitioning from the Royal Children's Hospital to the adult health service. The transition manager suggested I'd be a **good fit** for CP-Achieve's new advisory group for young adults. Initially, I hesitated, unsure of how much I could help. But I decided to give it a try and embrace the opportunity to try something new.

After starting with the advisory group, CP-Unite, I also expressed interest in being involved in individual projects. Sevastine, one of CP-Achieve's consumer coordinators, thought James and I would **work well together** because of our similar interests, and she connected us – it was my first role working directly on a research project.

I never thought, coming from an IT background, that I would be involved in research. I was worried whether I could help James and whether I would be a useful asset relative to someone with more complex forms of cerebral palsy. Once I knew what to do, how to help him and the type of information he was after, **it was easy going forward**.

Reflection point

How will you get started on your consumer involvement journey? What networks and services can you draw on to identify consumer research partners?

Good practice

Matching consumer research partners and researchers based on similar interests.

Consumer influence throughout the research cycle

James

Most of the consumer involvement in my PhD has been during the qualitative and feasibility studies, and it has involved a mix of seeking **feedback** from advisory groups and asking **advice** from consumer research partners. The protocol and research questions for the qualitative study had been established after completing my systematic review, so the role of the consumer research partners primarily centred on methods, implementation and sharing the results, as outlined in Table 18, below.

Gaurav

As a consumer partner, I provided feedback on the study's processes to ensure they **aligned with the needs** of adults with cerebral palsy. My involvement helped **refine** the research methodologies, including testing quality-of-life measurement tools and allowing James to practise some of his data collection methods. The process of giving feedback was **rewarding** and **enlightening**.

I feel like I have been able to help because of my cultural background. Being multilingual, I've been able to help James simplify the language and research processes to be more accessible to people with cerebral palsy.

Reflection point

What roles could consumers play in your project at different stages of the research cycle?

Table 18 Consumer roles in James' PhD program

Stage in the research cycle	Research activity	Consumer role
Designing the study	Designing interview process and questions	One Group Our Voice were consulted on the study design. They suggested adaptions that could be made to interview processes and questions if working with AAC[55] users.
		The consumer research partners gave feedback on the readability and accessibility of participant information letters, survey and interview questions. This assisted James in refining the research methodologies and quality-of-life measurement tools. Gaurav and Ann trialled the qualitative interview with James and provided feedback on his approach and style. Gaurav trialled the process of setting participation goals for the exercise intervention with James, providing feedback on his approach.
Implementing the study	Reviewing and organising results	Gaurav and Cassie worked with James to analyse results and select quotes that represented key themes of the qualitative study.
Sharing the results	Writing journal articles and presenting findings	Gaurav contributed to a journal article sharing qualitative study results. Gaurav presented a poster with James and gave an in-person contribution in partnership with James at the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) in Cairns in 2024.

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[55] Augmentative and Alternative Communication

Realising the value of consumer involvement

James

The first time I truly understood the value of involving consumers in the research process was when Ann and Gaurav helped **trial the interview process** for the qualitative component of my research. They role-played as participants while I went through the interview schedules, providing feedback on my interviewing technique. The experience did more than just confirm that involving consumers in the process was the right approach. It was a moment of realisation – having the consumer research partners involved was **incredibly beneficial**. Their support gave me the opportunity to **practise** the interview, **receive constructive feedback** and **build my confidence** before conducting interviews with actual participants.

As I began to recognise the benefits of involving the consumer research partners, I started thinking about other ways they could contribute to the project. I wanted my study to **truly represent the experiences and needs** of people with cerebral palsy, so it made sense to involve the consumer research partners more deeply in various aspects of the research.

Based on the success of the trial interviews, I involved Gaurav in **reviewing the outcome measurement process** in my third study. I really respect him as a worker. He pointed out that the survey was **excessively long**, taking him about 50 minutes to complete. Despite this, we decided to proceed. It took quite a lot of prompting to have surveys returned to me, likely due to the survey's length, just as Gaurav had predicted. I realised that I may have unintentionally contributed to **'bureaucratic trauma'**— trauma caused by being overwhelmed by numerous, in some cases pointless forms to access basic health and disability services. I won't make that mistake again.

Reflection point

How do you expect your research will benefit from consumer involvement?

Travelling together

James

Gaurav travelled to contribute to two research activities. The first was an **intervention trial** of an accessible beach day in Warrnambool, which involved an overnight stay. The second was a five-day trip to attend and **co-present** the results of our studies at the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference in Cairns. When Gaurav came to stay with me in Warrnambool, it was the first time he'd been away from home. Cairns was his **first trip interstate**. I feel fortunate to have been part of these **important milestones**.

In Warrnambool, we **trialled** the beach activities and then had some fun in the surf. It was just such a great afternoon, and it showed me that participating in surfing provides exercise with significant therapeutic value. That has really sparked my **interest and passion** to take that further and see how I can create a surf-based intervention for people with cerebral palsy.

The trip to Cairns was a really, really, good week. Gaurav's mum looked petrified when she dropped him off at the airport. Being a physiotherapist, I'm always thinking about physical and cardiovascular function, but there were all these other things I needed to consider on our trip to Cairns, such as **timetabling our activities** and making sure that Gaurav knew our **schedule** and had **food** that he was comfortable eating.

We arranged a snorkelling tour on the Great Barrier Reef on our last day. We had a wetsuit, we had a pool noodle, we had a rescue ring, we had a life vest and Gaurav went out twice and snorkelled on the reef, despite not being a strong swimmer. It was just brilliant.

Gaurav

The journey to South-West Victoria allowed me to **grow as a person** and experience many 'personal firsts.' My first road trip, my first sleepover and the exhilaration of swimming, surfing and riding the waves for the first time at Port Campbell Beach.

Pictured above: Guarav and James snorkelling on the Great Barrier Reef.

> “All my previous exposure to people with cerebral palsy had been through clinical relationships. I've really gained a different perspective of living with cerebral palsy, not just as a physio, not just as an exercise prescription – but the whole experience.”

James Czencz, PhD Candidate

Pictured left: Gaurav and James co-presenting a poster at the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference in Cairns.

Promoting accessibility and a sense of safety

James

Recognising that Gaurav had not travelled away from home before, I was very aware of the need to create a **safe and supportive environment** and not add to any stress that he already faced in daily life. To make the trips **accessible and safe** for him I focused on:

- providing **time** for Gaurav to make decisions and organise travel
- avoiding placing pressure on him to meet arbitrary deadlines
- providing **support for daily tasks**, as needed while we were away
- meeting specific **cultural needs**, including dietary preferences
- providing a detailed **schedule of activities** and adhering to it during the trips.

Gaurav

I tried surfing back in Year 7 at school, and it was not a great experience. I tried it again with James and I enjoyed it so much. He **took care** of me. He didn't want anything bad to happen, so he was **there for me**. We started with the basics and slowly progressed. Just trying that with him was a great experience. I also helped him with his research project, so it was a **win-win** arrangement.

During the trip to Cairns, James was there to **support me**, helping where needed and just being there as a **comfort**. If I had to go to the conference by myself, I would have been very nervous. Just having him there was a great thing. Meeting people was also easier with James, as he introduced me to his colleagues.

Funding for consumer involvement

Table 19 highlights the time investment of both consumers and the researcher to facilitate consumer involvement in this project. As per CP-Achieve policy, consumers were paid via gift cards at a rate of $40 per hour.

Table 19 Costs of consumer involvement in James' project

Activity	Consumer involvement (including preparation time, meetings, materials development and document review)	Researcher time to support consumer preparation (approximate)
Onboarding consumer research partners	3 consumer research partners x 2 hours = **6 hours**	3 consumer research partners x 1 hours (prepping induction slides, reading material, emails/administration) = **3 hours** 3 partners x 1.5 hours (induction meeting, post-meeting admin) = **4.5 hours**
Meetings with consumer research partners throughout the project	3 consumer research partners x 3 meetings + 30 minutes preparation for each activity = 15 hours 1 consumer research partner (Cassie) 2 x 2-hour meetings = 4 hours	Administration (agenda creation and distribution, meeting minutes write up) 1 hour per meeting x 8 meetings = **8 hours**
Reviewing project activities in Warrnambool	1 consumer research partner x 3 hours = **3 hours**	2 x 4 hours = **8 hours**
Preparing for joint presentations	1 consumer research partner x 2 hour = **2 hours**	1 x 1.5 hours presentation activity = **1.5 total hours**
Cairns presentation	1 consumer research partner x 2 hour = **2 hours**	1 x 1.5 hours presentation activity = **1.5 total hours**
Total time	32 hours	18.5 hours
Total cost	$1,280	

Benefits of consumer involvement

James

Involving consumers in my PhD research **motivated and assured me** that I was on the right track and could make a difference. As physiotherapists, or parents working with people with cerebral palsy, we've got to stop being the 'no'; we've got to start being the 'yes, let's make it happen. How can we do it?'

In terms of working with Gaurav specifically, we have developed a **strong friendship** through our working relationship that will last beyond this project. I really respect him as a worker. The quality of his work is above and beyond what anyone could ask.

Gaurav

When I stepped out of my comfort zone and opened myself to new possibilities, I experienced **transformative growth and beautiful new opportunities.** This **personal journey** allowed me to develop independence, self-confidence and social connections. I learnt how to advocate for myself, what is involved in conducting research, the different types of studies and participant groups. It was something I never expected I would be learning. Now that the research is ending, I am really going to miss working with James and CP-Achieve more generally.

Initially, it was a working relationship; over time we have become good friends. If I have anything I need to share with James (about the research or my disability) I can, and he can share with me too.

Impacts of consumer involvement on the research outcomes

James

In addition to the consumer research partners improving my research process and materials overall, One Group Our Voice provided great feedback on the qualitative study questions. They suggested ways my questions might be **adapted** or changed if I was working with someone who used AAC. Their suggestions included avoiding open-ended questions, focusing instead on the specific response I was targeting, to **reduce the burden** on the respondent. So rather than, asking 'Can you tell me about yourself?', they suggested that I first consider why I am asking this question, and what I want to know, and then ask a question that more specifically elicited answers that I was seeking. This feedback improved the questions and also gave me the **confidence** to work with individuals using AAC methods in my study.

Gaurav

I saw myself more as an Advisor than an Equal Partner[57] in the research, offering suggestions on what could be improved or changed for the better. I helped James as much as I could, sharing insights from my experience with cerebral palsy. While I did my best to contribute, I felt I could have done even more if James had involved me further.

Reflection point

How will you discuss expectations of involvement with your consumer research partners and ensure that these expectations are being met?

> "Often at the end of a research project, there can be a need to renegotiate boundaries. In some cases, it can be unclear whether the relationship is professional or has extended to friendship. Often the renegotiation can start with "Can we catch up for coffee"."

Carolyn Pinto, Consumer Coordinator

> "There are so many ways consumers can be involved in research. There is no right or wrong way if it is authentic and benefits both researcher and consumer."

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56 For definitions of these levels of influence, see Chapter 7: Involving consumers across the research cycle: Co-developing an online health literacy module.

James Czencz, PhD Candidate

> “My advice is, just start with a coffee and a chat and let it grow organically as your confidence grows. You’ll soon realise the value of consumer involvement.”

> “If consumers point out when something is not going well, celebrate! If consumers feel safe to speak up, you’re fostering a respectful partnership. Mistakes enrich the journey, and peer networks can help navigate them. Researchers should embrace consumer feedback and learn from mistakes.”

Associate Professor Margaret Wallen, Consumer Involvement Theme Leader, Chief Investigator

> “When I stepped out of my comfort zone and opened myself to new possibilities, I experienced transformative growth and beautiful new opportunities.”

Gaurav Thakkar, Consumer Research Partner, young adult with cerebral palsy

Advice for researchers

James

My advice is, just **start with a coffee and a chat** and let it grow **organically** as your confidence grows. You’ll soon realise the value of consumer involvement.

Gaurav

Include consumers in your research, including those with more complex forms of cerebral palsy. When I was working with James, I encouraged him not only to consider my insights but also to seek input from others with more complex forms of cerebral palsy. That broader perspective could be even more helpful – and he did just that, taking the idea on board.

Publications

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.

Key takeaways

Getting started with consumer involvement can feel daunting. Taking small steps, collaborating with consumers in just a few activities in the research cycle and at the consultant and advisor levels of influence, may feel more achievable.

Once consumer involvement starts making a real and meaningful impact on research, researchers are motivated to further develop the skills, confidence and passion to involve consumers in their research.

Chapter 11

Getting started: Steps for your journey

> “Now you’ve read about CP-Achieve’s consumer involvement journey, it’s time to get started on your own. To help you develop an approach relevant to your own context, this section has a summary of steps you can take, drawing from CP-Achieve’s experiences.”

Associate Professor Margaret Wallen, Consumer Involvement Theme Leader, Chief Investigator

Follow this link

To hear tips from the consumer involvement team and Consumer Research Partner, Gaurav Thakkar, on getting consumer involvement started in your project.

Steps to getting started on your own consumer involvement journey

This resource includes CP-Achieve's collective learning and experiences of involving consumers in health and disability research. It captures the joy, the richness and the challenges of five years of consumer involvement.

We outline 12 steps to **get you started** on your own consumer involvement journey, each cross-referenced to related content in this guide for added detail and resource material.

Good practice

Keep detailed records of all decisions and actions. We wish we had kept more detailed records to inform development of this resource.

1

Get started. Adopt a can-do attitude, use the experiences in this resource, and aim to involve consumer research partners in your research in small or substantial ways, depending on your confidence and resources.

2

Obtain organisational, management and leadership support for consumer involvement. Ensure their commitment to consumer involvement is overt and transparent.

3

Define your values around consumer involvement and overarching principles and practices that will drive your endeavours. Examples are building and establishing relationships, communication, accessibility, psychological safety, authenticity, impact, acknowledgement and payment[57].

4

Develop a consumer involvement plan, preferably in collaboration with consumers. Aim to:

- involve consumer research partners early and throughout the research cycle
  - identify the level or levels at which consumers will influence your work, from being informed through to leading the research
  - consider the scope of activities where consumer involvement will have impact, including systematic and scoping reviews, steering committees, advocacy and knowledge translation.

5

Seek funding. Funding will be needed for consumer payment and a range of other activities that support authentic involvement throughout the research cycle[58].

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[57] For a list of CP-Achieve's principles go to 3. Embedding Consumer Involvement across CP-Achieve

[58] For further information on budgeting for consumer involvement go to 4. Funding for Consumer Involvement

6

Designate consumer coordinator or liaison personnel. Identify who will take responsibility for and be committed to ongoing close collaboration with consumer research partners to build and sustain relationships, identify their goals for involvement, implement accessibility and support requirements, and monitor wellbeing.

7

Onboard consumer research partners. Consider:

- where and how to distribute invitations so that consumers will see that the invitation applies to them, that their involvement is genuinely valued, and that any access needs will be accommodated
    - extending invitations to seek diversity of experiences and backgrounds
    - seeking signed agreements or terms of reference outlining mutual expectations
    - orientation and preparation practices
    - meaningful ways of matching consumer research partners to advisory groups and/or projects and researchers.

8

Collaborate to establish ways of working with consumer research partners. Ways of working may include timing, frequency and duration of meetings, expectations outside meeting times, timing and nature of meeting agenda and preparation of materials, flexibility of commitment, communication modes and frequency, and accessibility considerations.

9

Commit to closing the loop – ensuring consumer research partners are aware of the impact of their involvement and receive study findings or outcomes in accessible forms.

10

Establish ongoing monitoring and evaluation of consumer involvement principles and practices to optimise authentic involvement. These may include informal check-ins with researchers and consumer research partners through to formal research evaluating processes.

11

Transition. Consider the impact that the end of a research project or program may have for consumer research partners and facilitate a transition process to support this change.

12

Reporting consumer involvement in presentations and publications lends credibility to the research, enhances the profile of consumer involvement in research, and importantly acknowledges the contribution of consumer research partners to the research.

Working examples of CP-Achieve resources

CP-Achieve has numerous working examples of forms and resource documents used during the program to share with other research projects. These are summarised in Table 20.

Forms can be accessed on CP-Achieve's page at MCRI: www.mcri.edu.au/research/strategic-collaborations/centres/centre-research-excellence-cerebral-palsy

Table 20 Working examples of forms and resource documents

Form used during CP-Achieve	Description
Consumer coordinator Job Description	This job description outlines the roles and responsibilities of the consumer coordinator.
CP-Achieve Diversity Strategy	This strategy was developed to promote greater diversity in CP-Achieve's Parent Advisory Group.
Orientation to Consumer Involvement, Session for Consumers	The presentation was used in orienting consumers to CP-Achieve and consumer involvement.
Welcome Pack	The welcome pack provided consumers with information about CP-Achieve and consumer involvement opportunities.
Expression of Interest (EOI)	The Expression of Interest form was created to capture the details of interested consumers for targeted research opportunities.
Letter of Agreement	The Letter of Agreement outlined the roles and responsibilities of consumer research partners and was used when consumers joined research teams or advisory groups.
Consumer Profile	Consumer profiles were developed for each consumer as they became involved in research. These were critical as a starting point for developing a relationship with consumers, identifying consumer support needs, matching consumers to projects and to showcase on CP-Achieve's website.
Consumer Involvement Planning and Budget Application Form	The Consumer Involvement Planning and Budget Application Form assists researchers to thoughtfully plan how, when and why they would involve consumers in their projects. It also serves as a request for consumer involvement funding, and for assistance in identifying consumers. Beyond planning and budgeting, the form facilitated discussions between researchers and the consumer involvement team, fostering learning about best practices and offering examples of consumer involvement across different stages of the research cycle.
Meeting Plan	This plan designed by researchers and provided to consumer research partners prior to meetings, highlights the activities to be held in the meeting, along with key questions that will be asked to facilitate consumer preparation.

Chapter 12

The CP-Achieve ‘Family’

> CP-Achieve’s ‘family’ are listed here – all the consumers, researchers and staff who contributed to driving good consumer involvement practice.

Professor Dinah Reddihough,
Principal Investigator

Research program

Research Program

Principal Investigator Dinah Reddihough

Program 1	**Program 2**	**Themes**
Improving the physical and mental health of adolescents and young adults with cerebral palsy.	Building supportive family, community and health service environments that help young people take part in life situations that are important to them.	Consumer involvement. Promoting participation. Health economics. Developing a specialist workforce.
David Coghill Program 1 Leader, CI Kerr Graham, CI Susan Sawyer, CI Evelyn Culnane, AI Gabrielle Drake, AI Leanne Johnston, AI Jane Tracy, AI Sarah Giles, Postdoctoral Research Fellow Carlee Holmes, Postdoctoral Research Fellow Iain Dutia, Honorary Fellow	**Prue Morgan** Program 2 Leader, CI Ingrid Honan, CI Bruce Bonyhady, AI Mats Granlund, AI Jan Willem Gorter, AI Peter Rosenbaum, AI Lyndal Hickey, AI Leanne Sakewski, AI Stacey Cleary, Postdoctoral Research Fellow	**Christine Imms** Participation Theme Leader, CI **Margaret Wallen** Consumer Involvement Theme Leader, CI **Nora Shields** Specialist Workforce Theme Leader, CI **Rob Carter** Health Economics Theme Leader, CI

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Jocelyn Cohen
John Carey*
Kate Anderson
Kathleen Ooi
Loretta Sheppard
Michelle McInerney
Petra Karlsson
Rachel Toovey
Sue Reid
Utsana Tonmakuyakul*
Ximena Camacho

*Also a higher degree research student.

Higher degree research students

CP-Achieve postdoctoral candidates

Georgia McKenzie
Jacinta Pennacchia
Jacqueline Ding
Megan Walsh
Nadine Smith

Associated higher degree students

Katie Headrick
Rowan Johnson
Kerry Britt
Magnus Ivarsson

Consumer research partners

Parents	Adolescents	Young adults	AAC users
Bianca Brant	Feona Magtanum	Abbey Potter	Brodie Shaw
Chris Pacheco	Jet Johnson	Alana Jovanovski	Penny Manning
Ebony Gough	Kyra Culloten	Alexa Yao	Shirls Wong
Helen Briffa	Kai Armstrong	Alex Birnie	Brenton Ponza
Helen Tossell	Ivy Rogers	Alesia Lu	
Janine Stanley	Sam Higgins	Caitlin Doyle	
Janine Stanley		Cassandra Assaad	
Joan Gains		Freya Munzel	
Julie Dean		Gaurav Thakkar	
Kylie Brown		Greg Bonyhady	
Meg Smith		James Plummer	
Michelle King		Natasha Jones	
Michelle Roger		Nicole Kozelj	
Toni Green		Oliver Hunter	
Wendy Pritchard		Rohan Symonds	
		Shanee Holmwood	
		Tess Pearce	

Operational team

Carolyn Pinto
Consumer coordinator, families

Sevastine Katsakis
Consumer coordinator,
young people

Deborah Markelis
Research coordinator

Claire Rowland
Consumer involvement
translation fellow

Chapter 13

Index of key themes

> This Index allows for you to search across the resource for common themes that are dotted throughout the stories.

Carolyn Pinto,
Consumer Coordinator

Acknowledgments

Special thanks to CP-Achieve's Chief Investigator Dinah Reddihough and Consumer Involvement Theme Leader Margaret Wallen for your consumer involvement vision and to Consumer Coordinators Carolyn Pinto and Sevastine Katsakis for your passion and thoughtful delivery of consumer involvement services. All the consumer involvement champions featured deserve a big thank you for generously giving their time to develop this resource. Thank you to all of CP-Achieve's staff, researchers, and consumers who worked to create innovative, fit-for-purpose, targeted research that benefits young people with cerebral palsy. This is your story, and we hope you are proud of it. This resource would not look the same without the creativity, insight and direction of the Knowledge Translation Advisory Group members Kate Anderson, Megan Finch-Edmondson, Kirsty Stewart, Joan Gains, Nyanhial Yang and Ken Knight, and the enthusiasm of Deb Langridge. Finally, thank you to Deb Langridge, Kate Anderson and Joan Gains for your generosity and sharp eyes in the editorial process.

The authors acknowledge and pay our respects to the Traditional Owners and Custodians of the lands on which we live and work. We recognise and honour the importance of Aboriginal and Torres Strait Islander peoples' spiritual and cultural connection to Country. Sovereignty of the lands and waterways, which Aboriginal and Torres Strait Islander peoples have cared for and nurtured for millennia, has never been ceded. They always were and always will be Aboriginal and Torres Strait Islander peoples' lands and waterways.

We acknowledge the individual and collective contributions of those with a lived and living experience of cerebral palsy and those who love and care for them.

For any questions or concerns accessing these materials online, please contact Dinah Reddihough at dinah.reddihough@mcri.edu.au.

murdoch
children's
research
institute

CP-ACHIEVE
Centre of Research Excellence