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Participating together in CP-ACHIEVE: Experiences, opportunities and reflections from a collaborative research team of people with lived experience of cerebral palsy and health care professionals

Gaela Kilgour
University of Queensland, Australia

Alesia Lu, Nicole Kozelj and Jane Tracy
CP-ACHIEVE at the Murdoch Children's Research Institute, Australia

Lyndal Hickey
University of Melbourne, Australia

Mats Granlund
University of Jonkoping, Sweden

Nora Shields
La Trobe University, Australia

Prue Morgan
Monash University, Australia

Gabrielle Drake
University of Western Sydney, Australia

Stacey Cleary
Murdoch Children's Research Institute, Australia

Leanne Johnston
The University of Queensland School of Health and Rehabilitation Sciences, Australia

Christine Imms
University of Melbourne, Australia

Corresponding author:
Gaela Kilgour, University of Queensland, Brisbane, Australia.
Email: g.kilgour@uq.edu.au

Abstract

The Australian Centre for Health, Independence, Economic participation and Value Enhanced care for adolescents and young adults with Cerebral Palsy (CP-ACHIEVE) is a Centre of Research Excellence (CRE), funded for 5-year by the National Health and Medical Research Council of Australia. The vision of CP-ACHIEVE is an Australia where people with cerebral palsy receive excellent healthcare throughout their lives and live in, and contribute to, supportive communities that welcome and enable their participation. CP-ACHIEVE began with the ethical commitment to bring together people with lived experience of cerebral palsy, researchers, and health professionals to develop and conduct research informed by, and relevant to, people with cerebral palsy and their allies. From inception, co-research and collaboration with (not 'to' or 'about') young people with cerebral palsy (10 to 30 years of age) and their families has been central to our work. In this paper, we describe the CP-ACHIEVE values, structure and strategy for this approach, and its implementation at each stage of the research process. We then provide an example of the strategy in action, using a qualitative exploration of CP-ACHIEVE's Participation Theme team's experiences of collaboration and involvement as co-researchers. Active participation in research for young people with lived experience of cerebral palsy and their families is a fundamental human right, based on their right to be active agents in decisions that affect them. In this paper we explore how our collaborative approach, and the integration of diverse views, has enhanced the relevance, quality, usefulness, and translation of our research. We also describe (i) the structural elements of our research group that have facilitated our work together, (ii) our challenges, and (iii) how the ownership of our research by people with cerebral palsy is driving future research directions and empowering involvement of people with lived experience beyond CP-ACHIEVE. We offer this knowledge and our experiences to assist other research teams in their journeys towards collaborative research alongside people with lived experience of disability.

Keywords

Cerebral palsy, participation, collaborative research, co-research, involvement, patient and public involvement, children, young people

Introduction

In health research, partnerships have traditionally included professionals within the same or similar disciplines. More recently, the commitment to research informed by consumer priorities has led to a shift in research partnering inclusive of consumers from a project's inception. These partnerships have led to co-produced research that is relevant, appropriate and informs health practice in a meaningful way. Co-production is one of several terms (e.g., co-design, co-creation) used to describe the actions of 'doing research' collaboratively with consumers and other stakeholders (McGill et al., 2022). Consumer involvement in research has become part of funding requirements within many Australian research grants, such as those funded by the National Health and Medical Research Council (NHMRC, 2016).

There is growing evidence that children and young people with disabilities such as cerebral palsy are interested in being research partners and want to have an active role in research that directly impacts them (Cavens et al., 2022). In addition, research partnerships with parents and caregivers of children with cerebral palsy are seen as beneficial for the research and the consumers (Headrick et al., 2023). To support involvement, researchers need to acknowledge and value the expertise of people with lived experience (children, young people and their parents/caregivers) and develop strategies to enable active, flexible, and sustained involvement (Cavens et al., 2022). Parents emphasise the importance of forming lasting relationships to enable collaborative partnerships through all stages of research (Headrick et al., 2023). This paper outlines our consumer involvement processes used to partner with young people with cerebral palsy and parents of young people with cerebral palsy in our Participation Theme team within the Australian Centre for Health, Independence, Economic participation and Value Enhanced care for adolescents and young adults with Cerebral Palsy (CP-ACHIEVE). In this paper we use the terms 'adolescent' to refer to those aged 10 to <19 years (https://www.who.int/health-topics/adolescent-health#tab=tab_1), 'young adult' for those aged 19 to 30 years, and 'young people' for the collective age group of 10 to 30 years.

This paper was co-produced with the whole authorship team, including two members who are young adults with cerebral palsy (AL, NK) and a parent (JT). Drafting of the content occurred within smaller subgroups of writers (e.g., development of recommendations occurred between AL, NK, GK; drafting of content of results occurred in full team meetings). All authors reviewed and commented on all aspects of the paper as it evolved, and approved its submission.

CP-ACHIEVE aims, values and structure

CP-ACHIEVE is the Australian Centre for Health, Independence, Economic participation and Valued Enhanced care for adolescents and young adults with Cerebral Palsy. It is a Centre for Research Excellence (CRE), a 5-year program of research funded by the NHMRC of Australia. The focus of CP-ACHIEVE is on supporting adolescents and young adults with cerebral palsy, aged 10 to 30 years, to live a full and healthy life. This age range is in focus because as people with cerebral palsy age, their health, social and service needs change. Despite substantial research on the health and development of infants and children with cerebral palsy, an almost complete research void exists around the needs of this older marginalised group of approximately 14,000 Australian adolescents and young adults living with cerebral palsy (ACPR Group, 2018; Australian Cerebral Palsy Register Group, 2009; Solanke et al., 2018). CP-ACHIEVE includes individuals up to 30 years in recognition of delays in life and health transitions commonly experienced by those with cerebral palsy, and to capture the experiences of adult health care beyond the period when transition clinics typically cease (16 to 25 years). Health issues for all young people are significant during adolescence. Puberty changes the trajectory of many health problems, including heightened psychological vulnerability;

these are critical years for onset of serious mental health disorders (Bonnie et al., 2015). Common milestones across these years include: completion of primary and secondary education, transition to higher education, vocational training and employment, moving out of home, and first intimate peer relationships. Success in achieving these milestones has long-lasting implications for future health, wellbeing, community participation, and economic security.

CP-ACHIEVE research takes a lifespan perspective and aims to support people with cerebral palsy to (i) improve their physical and mental health, (ii) access and receive excellent health care, and (iii) participate in relationships, work, leisure, physical activity and the community, as they transition towards and through young adulthood. Central to this program of research is the commitment to bring together people with lived experience of cerebral palsy, researchers, and health professionals to develop and conduct research relevant to young people with cerebral palsy. From the beginning, collaborative research with (not 'to' or 'about') young people with cerebral palsy and their families has been essential. These CP-ACHIEVE values are reflected in the research strategies and structures of our program of work, in the development of our research teams, and in the allocation of resources.

CP-ACHIEVE has been structured with four 'embedded' themes, elements that are to be included in the research projects undertaken: authentic consumer engagement, promoting participation, health economic analysis and productivity, and clinical and research workforce development (see Figure 1). Each of the embedded themes has a chief investigator with oversight. Chief investigators are supported by a working group who collaborate to consult with researchers across all CP-ACHIEVE projects on integration of theme elements within a planned project, and further the research of the theme area.

Supporting optimal participation in life situations that are important to young people with cerebral palsy and their families, such as education, employment, and community activities, is the intended outcome of CP-ACHIEVE research. Because participation occurs in context and is an outcome of the interaction between the person and their environments (Imms et al., 2017), our research is undertaken as two programs of work. Program 1 is focused on improving physical and mental health, and Program 2 on building supportive environments. The goals of Program 1 are to quantify physical and mental health outcomes and understand the impact of health outcomes on participation over time, in young people with cerebral palsy aged 10–30 years. Program 2 research aims to build evidence about what is needed to ensure participation in important life situations is possible for young people with cerebral palsy living in Australia. This involves building new evidence about what works to support participation in physical activities (an essential element of health promotion), as well as to translate available evidence-based participation intervention programs to the Australian context.

Participation in CP-ACHIEVE

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations General Assembly, 2007) establishes the right of people with disability to "full and effective participation and inclusion in society". The UNCRPD does not,

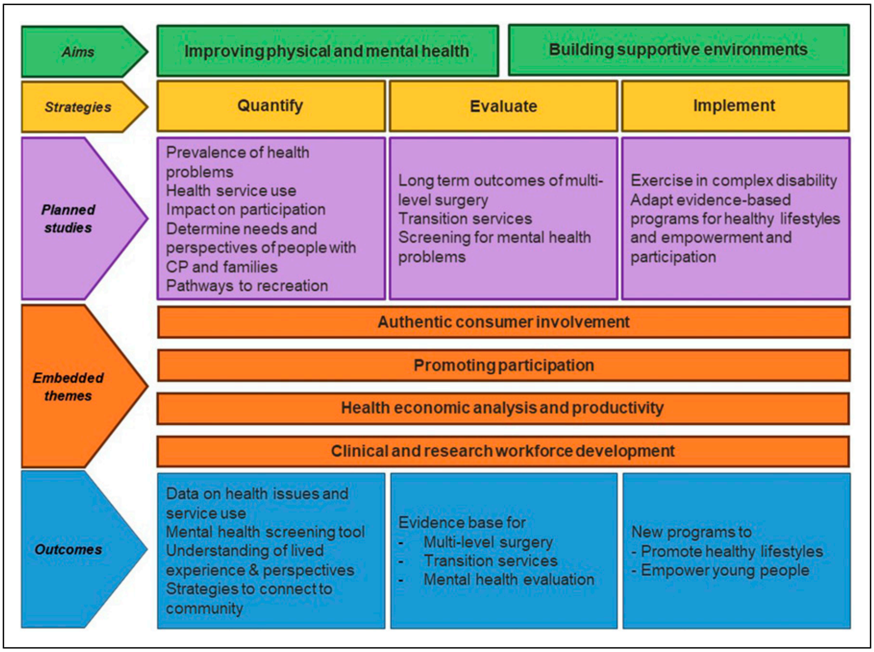

Figure 1. The structure of the CP-ACHIEVE research program as planned.

however, explicitly define participation, nor inclusion, which can make it difficult to identify effective strategies to assure effective participation. We define participation according to the Family of Participation Related Constructs (fPRC) (Imms et al., 2017), as involvement in a life situation that has two essential elements; attendance, and involvement. Attendance is defined as 'being there' - being present in a life situation, and involvement as the 'experience' of participation while attending. The two elements are universal and thus applicable to all life situations. Because 'attendance' is an observable construct, it is often what is measured, for example, percentage of children with disability attending school. According to the fPRC, attendance is a necessary but not sufficient condition for involvement in any life situation and the framework proposes that assuring *involvement* is the means to meaningful and effective participation. The fPRC is grounded in the biopsychosocial framework of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) and provides a framework for optimising participation and reducing participation restrictions. The goal of the fPRC framework is to support equity of participation by identifying what is needed to solve participation problems and/or assure effective participation attendance and involvement.

Participation in research is one meaningful and important life situation that young people with cerebral palsy and their family members have a right to take part in, and this belief underpins the approach of CP-ACHIEVE to involvement of consumers as research partners. 'Consumers' as defined by Australia's National Health and Medical Research

Council (NHMRC), are “people who use health care and support services and their caregivers” (NHMRC, 2016: 6). Consumer attendance and involvement in each phase of the research cycle within the CP-ACHIEVE program of research is thus a means of ensuring we conduct relevant, significant, and useful research.

Consumer involvement in CP-ACHIEVE

Participation in research uses a range of terms to describe the individuals involved, including patient and public involvement (Brett et al., 2014), lived or living experience (Padwa et al., 2023) and consumer (NHMRC, 2016; Smith, 2021). The young people with cerebral palsy we engaged with chose to be referred to as ‘consumers’. They expressed their view that this term gave credence to their rights as decision makers around research conduct and research use. Hence, ‘consumer involvement’ in CP-ACHIEVE means that the research is carried out with young people with cerebral palsy and their families. Individual consumers can be involved in ways that they choose; as listeners, co-thinkers, advisors, partners and/or decision makers (Smits et al., 2020) in any or all stages of a research cycle by taking part in reference groups, advisory panels or as investigators in research teams. In CP-ACHIEVE, consumers contribute to decisions about priority topics to research; research questions to explore; methods used to carry out the research; data collection, analyses, and interpretation; and how best to share and disseminate the results of the research with others.

Establishing *how* we would work together in CP-ACHIEVE involved developing a Consumer Involvement Strategy and guiding principles and processes for all research projects (Wallen et al., 2020). Our strategy was developed with guidance from the Public Involvement Impact Assessment Framework (PiiAF) (Popay et al., 2014). Consistent with PiiAF, we established our values and approaches to involvement, including how we would evaluate the impacts of involvement.

Our values include *commitmen*t to our ethical responsibility to research with young people with cerebral palsy, and to centring the voices of our consumer groups so their lived experience is integral to CP-ACHIEVE. Our approach values open and accessible communication that ensures collaborative, trusting and respectful relationships, to encourage diversity of opinions and to support flexibility of involvement. We acknowledge and support involvement through recognition that sensitive topics may be confronting, and people may require support, that individuals bring varying levels of cognitive and communication support needs, and that payment of time given is fundamental to acknowledging value of contribution, as was acknowledging contributions through shared authorship in publications, presentations, and other dissemination activities.

Strategies for consumer engagement and participation in research

One key enabler of our consumer involvement approach is dedicated funding within our CP-ACHIEVE program. The CP-ACHIEVE budget includes funding to pay for the following staff: a consumer coordinator (a parent of a young person with cerebral palsy), and a project officer (a young adult with cerebral palsy), and a consumer theme leader (one of our chief investigators, contributed in-kind) (see Figure 2). Additionally, there are

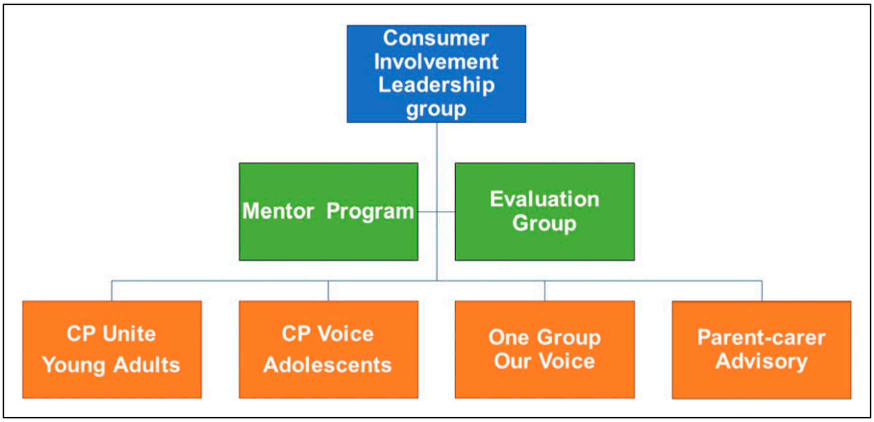

Figure 2. CP-Achieve's consumer involvement team. The leadership group comprises a chief investigator, a consumer coordinator (a parent) and consumer support officer (young person with cerebral palsy); the mentor program comprises research and undergraduate students; the evaluation group includes the team around a doctoral student; CP Unite comprises young adults with cerebral palsy; CP Voice comprises adolescents with cerebral palsy; One Group Our Voice comprises young people with cerebral palsy and complex communication needs.

allocated funds that researchers within CP-ACHIEVE can apply for annually, to support involvement of individual consumers as research partners, and/or engagement with our consumer advisory groups. Financial support is limited. Every research grant application submitted by the CP-ACHIEVE team is expected to include appropriate budget items to support consumer involvement. CP-ACHIEVE has a dedicated Consumer Involvement Theme that consists of four consumer advisory groups that our researchers can engage with, and multiple individual consumer research partners involved in 31 studies that are in progress. The CP-ACHIEVE self-named advisory groups are: CP Unite, a group of young adults with cerebral palsy (ages 19-30); CP Voice, a group of adolescents with cerebral palsy (ages 10-18); One Group Our Voice, a group of young people with cerebral palsy and complex communication needs (ages 18-30); and a parent advisory group (see Figure 3). The core group leading the participation theme of the CP-ACHIEVE program comprises young adults with cerebral palsy, parents of young adults with cerebral palsy as well as health professionals and researchers.

In summary, CP-ACHIEVE research teams:

- Involve consumers from the beginning to decide what to research; plan the design and methods; carry out the research; analyse findings; and ensure that the findings reach and inform the people who need to know in the best ways.
- Find creative, appealing, and effective ways of involving young people, young adults, and families from across Australia including those who have significant physical disability, sensory impairments, communication difficulties and/or intellectual disability.
- Undertake research that will make an important difference to the lives of young people with cerebral palsy.

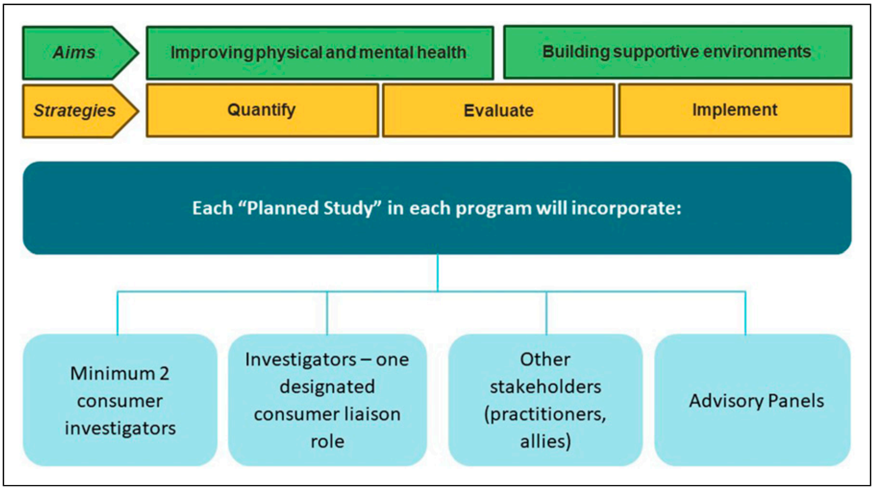

Figure 3. How the consumer team is used across the research projects within CP-ACHIEVE.

The Participation Theme team

Given the importance of 'participation' to the process and outcomes of CP-ACHIEVE, we established a Participation Theme team. At the start of CP-ACHIEVE, this team involved investigators with an interest in participation, including two investigators, a mother of a young man with cerebral palsy who requires advocacy to be represented, and the father of two young adults with cerebral palsy. As soon as our first consumer advisory group was formed, CP Unite, we met to establish consumer informed participation research priorities for CP-ACHIEVE. This included co-designing the participation survey for Program 1 and identifying the priority life situations that are in focus for Program 2. Two members of the CP Unite advisory group, young adults with cerebral palsy, joined the Participation Theme team as co-researchers. Our Participation Theme team now comprises thirteen members. Group members also bring expertise as allied health researchers and clinicians in areas of occupational and physiotherapy, psychology, social work and medicine, spanning the life course. Our work is intergenerational, involves people with a wide range of experiences in community, clinical and research contexts, fosters collaboration and co-production between those with lived experience of cerebral palsy and those with research and clinical experience. We have met for one hour per month for the past two years to:

(a) Support researchers within CP-ACHIEVE to consider how best they design, promote, measure, and analyse elements of participation within their research, across the important life areas of young adulthood, and
(b) Further our understanding of participation for young people with cerebral palsy in young adulthood and promote participation during this life stage.

Aim

The aim of this paper is to provide a practical example of the CP-ACHIEVE consumer-involved research strategy and structure, drawing on the Participation Theme team's experiences of collaboration and involvement as co-researchers.

Method

Design

Participating in this consumer-focused research team has been a new experience for many of our group. We have progressively developed our ways of working and researching together. We started without a clear roadmap for completing the day-to-day tasks, navigating roadblocks, and understanding the methods available for changing direction, as needed. This work is a descriptive, narrative exploration of the functioning of a team.

COVID restrictions meant that our initial meetings were required to be online. This has been continued throughout the project as members of the research team have found online meetings preferable in order to avoid transport logistic challenges and travel time. This applied to both the researchers with lived experience of cerebral palsy and other team members who were dispersed geographically.

At the half-way point of our funding period, we wanted to understand how we:

- have functioned as a collaborative team
- have each experienced our participation in the team as co-researchers
- need to adjust and improve our practices
- can share our processes with others, and
- need to focus our attention for the second half of our funding period.

To meet these aims, we decided to design and conduct a review of our team using a semi-structured group conversation to draw out our reflections and inform future plans. Two researchers with lived experience of cerebral palsy and a postdoctoral fellow, all members of the Participation Theme team, developed a series of explorative review questions, prompts, and considerations. These were further developed through an iterative process with the wider team.

A 90-minute, whole-team online conversation time was scheduled. The conversation-guiding questions, prompts, and list of considerations were placed on a virtual whiteboard accessible to all team members. Four broad questions guided the focus of our discussion:

(1) Why is active participation essential to CP-ACHIEVE research?
(2) What has your experience been like?
(3) What has gone well?
(4) What has gone poorly?

Team members added their thoughts, responses, and reflections to the virtual whiteboard in the two weeks prior to the team conversation, during the team conversation, and for up to four weeks following the session.

Data analysis

Ideas generated and recorded on the virtual whiteboard were collated, inductively analysed and synthesized into preliminary thematic categories (Clarke and Braun, 2017) by two theme team members, GK and CI. The proposed themes were further discussed and interpreted during a subsequent theme team meeting. The fPRC framework (Imms et al., 2017) was subsequently used as an organising framework to consider the extent to which our theme team was achieving the CP-ACHIEVE aims related to collaborative participation in research as a life situation. Final thematic analysis was a collaboration between all theme team members.

Our two co-researchers with lived experience of cerebral palsy (AL and NK) and a post-doctoral researcher (GK) further reviewed the ideas and preliminary themes with a focus on informing the “Next Steps”. We discussed:

(1) How do we use what we have developed?
(2) What’s next – how to share our learnings?
(3) What now – what needs to be done differently?
(4) Are we meeting CP ACHIEVE aims and promoting participation?

The results of these discussions were shared and discussed again with the theme team, to collectively consider: What do we keep doing? What do we want to start doing? And What should we stop doing? What else should our next steps consider?

Results

The results provide a qualitative self-reflective exploration of our Participation Theme team’s experiences of collaboration and involvement as co-researchers. In reporting our findings we have not attributed quotes to people or subgroups of people given the self-reflective nature of this work and the risk of identifying individuals. This approach is consistent with Morse and Coulehan (2015) recommendations for qualitative health research. The exploration of our first 2.5 years of work identified key themes for involvement as the ‘experience’ of participation in the Participation Theme team. Our reflective work found ‘being involved’ included both collective and individual responsibilities and opportunities for participation to be meaningful and valued. The experience of ‘being involved’ was distilled to three core themes: Being a valued partner, Being equitable, and Being ethical. While challenges were experienced, all team members considered the content of the themes supported the CP-ACHIEVE aim of consumer-involved research. Key quotes have been extracted to illustrate themes, and differences and similarities between the team as a whole and individual team members experiences are highlighted in Table 1.

Table 1. Individual and collective similarities and differences in experiences of involvement within the Participation Theme team by results theme.

Collective team experience	Individual team member experience
Being a valued partner	*Being a valued partner*
Being partners	*Being partners*
Shared commitment and understanding of the role of research partnerships with people with lived experience Reciprocity of learning	Shared commitment and understanding of the role of research partnerships with people with lived experience Partnering during all phases
Being valued	*Being valued*
Participation as research partners will enhance outcomes	Participation as research partners will enhance outcomes
Commitment to collaboration honoured and highly valued	
Being resourced	*Being resourced*
Time and resources to partner	Time and resources to partner
Being valued by funding bodies	
Being equitable	*Being equitable*
Centrality of involvement	Responsibility for being the voice for one or many
Equal empowerment	Respect, validating
Enable and promote diverse representation	Enjoyable and enlightening
	Supportive, welcoming, productive
	Confidence to speak up
Being ethical	*Being ethical*
Sense of ethical responsibility to hear the voice of all people with cerebral palsy inclusive of diversity	Sense of ethical responsibility to hear the voice of all people with cerebral palsy inclusive of diversity
Acceptance of work still to do	Acceptance of work still to do

Theme: Being a valued partner

The theme Being a valued partner includes subthemes of ‘being partners’, ‘being valued’ and ‘being resourced’.

Being partners: Our co-researchers with lived experience felt the CP-ACHIEVE framework and proposed opportunities for participation were being delivered. They described the multiple avenues to participate (attend and be involved) including being an active voice on advisory groups, co-researching as equal partners on specific research projects, and co-designing from the beginning of CP-ACHIEVE. They have also had opportunities to be research participants in some studies. New opportunities had arisen over the 2.5 years with the development of the research plans and strategies. Integral to their participation was an understanding that their research work might be time-consuming, required specific expertise, and in turn should be, and was, compensated with appropriate payment.

Being valued: All Participation Theme team members identified their experiences of partnering with consumers was beneficial to the research and to members personally, with the CP-ACHIEVE team fostering mutual respect and understanding from its inception.

> The voices of people with cerebral palsy have been central threads to this project from its inception, and throughout its development and implementation. The inherent essential nature and value of this approach to the project has been recognised and demonstrated since the beginning.

Experiences were described as positive, validating and empowering:

> Engaging and collaborating with colleagues has been rewarding especially as all members value each other. Coming into this team as an individual with lived experience, I was unsure of the power I would hold, but I have been met with nothing but opportunities to thrive and be heard.

Being resourced: A major challenge identified was being able to demonstrate to funding bodies that collaborative research was not only valuable but worth funding i.e., including payment of co-researchers.

> To do this well, takes more resources than we usually have.
>
> We need funding bodies to really understand and value the input, processes and benefits, to the research outcomes – as we do! – as the financial outlay is not insignificant.

Theme: Being equitable

Partnering could also present challenges to ensure accessible and equitable participation, allowing enough time to achieve outcomes and develop relationships where everyone was confident to share their ideas. As a group, there was an acceptance of "there's more work to be done" to ensure greater diversity in partnering, however the partnering that is occurring was experienced as reciprocal, productive, supportive and enjoyable for all.

> It's been a great help having more than one person with lived experience on the team – good to have differing opinions and others picking up on missed ideas. It's also a confidence boost when people agree with your points.

The Participation Theme team acknowledged that a serious challenge to achieving equity related to the lack of cultural, age and gender diversity within the team (all women but two). A targeted recruitment approach only elicited two applicants, both of whom became part of our team. Our young adults with cerebral palsy acknowledged their contribution to the group was possible due to their level of understanding of research and having studied at tertiary level, which may not be a choice for all people with cerebral palsy and not representative of those who require more assistance in their daily functioning. All team members acknowledged a need for different approaches to achieve effective research collaboration with people from culturally and linguistical diverse backgrounds, Aboriginal and Torres Strait Islander peoples. This is a current gap in our team. Critical reflections included partnering with parents and young people with lived experience whose voices are often not heard:

> What about the voices of people who are no longer engaged in services we are connected to, hard to reach, whose needs have been poorly met, and therefore whose voices are really important.

The ideal group size and representation of people with lived experience was discussed. Our team reported great value and respect in co-researching with parents and expressed the need for their active contribution to continue to help reinforce their voice. The balance of health professional numbers, skills, areas of interest worked well, but may need future consideration. The geographical spread of the group was limited to urban areas, exclusive of rural and remote experiences. Our co-researchers felt filling any gaps with people with lived experience could be done but wondered about the cost to an already established and well-functioning team. They expressed concerns at the time required to upskill, and that new voices may 'get lost'. While everyone currently felt they had an equal voice, they also thought that new recruitment of people to the theme team could address the identified gaps.

Theme: Being ethical

The theme team felt a strong ethical responsibility to hear, share and present the voice of people with lived experience of cerebral palsy, consistent with the principle: "Nothing about us, without us".

> I don't think it is in anyway reasonable to do research as 'researchers alone' [i.e., those without lived experience] – it is a breach of rights and limits what we can learn.

There were also challenges for those with lived experience, with their voice being their own, but sometimes an expectation that they would representing many: "Always important to differentiate between asking a person for their individual opinion and expecting them to represent their peers or wider group". This challenge was heightened for one of the team:

> The role of young people with CP is central to all we do. Parents also have a crucial contribution to make. I strive to contribute both my own perspective as caregiver, advocate and decision maker. I also try and represent my son so his voice, needs and priorities are heard as he is not able to speak for himself because of severe communication and cognitive difficulties. I have appreciated having my expertise and experience valued. The opportunity to contribute to a project that will impact on better understanding of the lives and health needs of people with cerebral palsy is tremendously important to me. I have greatly valued the perspectives, expertise and experience of the young people with CP working on this project.

Discussion

The aim of this article was to describe the CP-ACHIEVE strategy for research ‘with’ and not ‘to or ‘about’ young people with lived experience of cerebral palsy and its implementation at each stage of research. CP-ACHIEVE has embraced the concept of partnering with consumers in research with full inclusion, collaboration and consultation with young people with lived experience of cerebral palsy and their families. Using a reflective process, the Participation Theme team undertook a review of our collaborative processes to identify positive and negative aspects of this approach in research, sharing what we have learned with other researchers interested in collaboration and to consider what needs to be further developed to improve what we do. Use of the fPRC (Imms et al., 2017), enabled understanding of our Participation Theme team’s work as the ‘experience’ of researching collaboratively within CP-ACHIEVE as a life situation. Team members identified that collective and individual experiences of involvement led to meaningful, valued and collaborative research work. Being ‘involved’ required team members to be motivated, engaged, persistent, and they felt satisfied with their participation. In addition, a strong sense of social connection and positive affect was important to the success of the team. These reported experiences are consistent with the hypothesised relations among participation-related constructs in the fPRC (Imms et al., 2017). For example, there is a hypothesised transactional exchange between the individual and context (defined as the people, place, activity, objects and time) where the context can provide or regulate the opportunity for an individual’s participation and they in turn respond and influence the context. In our experience the context (the Participation Theme team’s research activities) provided an accommodating and acceptable setting for collaborative research. However, it appears that our methods of reaching consumers do not provide this opportunity for those from diverse communities. Thus, addressing the elements of the context that act to exclude, or to appear unwelcoming or irrelevant, is needed.

Our work and planning around consumer involvement has been informed by the fPRC because the framework has provided a structure for planning our approaches and ways of thinking about participation across varied life situations. While the fPRC was developed through child-onset disability research focused on the notion of participation as defined in the ICF (World Health Organisation, 2001), it is consistent with other participatory models that consider what is needed for authentic participation. For example, the Lundy (2007) model of participation was developed to support meeting the rights of children to express their views and for those views to be given due consideration (as per Article 12 in the United Nations Convention on the Rights of the Child, 1989) (UN General Assembly, 1989). This right relates to participation in decision making. Lundy (2007) describes four inter-related elements that are required to assure the right of children to have influence over decisions that affect them: (i) space - the provision of (a safe) opportunity, (ii) voice - support to express views, (iii) audience - access to the decision makers; and (iv) influence – that decision makers are open to being influenced by views expressed. The findings of our reflections suggest that the approaches taken do create research contexts in which participation attendance and involvement can be realised; not only in decision making but also in developing research strategies and learning from results obtained and that the context meets consumer rights to be influential in research decision making.

Overall, the Participation Theme team found the CP-ACHIEVE concepts of co-research were highly valued - to the extent of being ‘non-negotiable’ in disability research. All research team members felt welcome and recognised as equal contributors to the work of the Participation Theme. Team members shared a sense of individual and collective responsibility for the success of the research process. The extent to which team members were expected to be involved in the research process was agreed at the outset and reviewed according to the research activity or phase within the project. Regular reviews allowed for research team members to engage in new opportunities for research collaboration. In addition to these positive aspects, there was also universal agreement within the team that the implementation of the collaborative process provided valuable learning opportunities about conducting disability research. These learnings were already starting to shape the way research team members thought about future research with the Participation Theme and CP-ACHIEVE.

Alongside these positive aspects, the Participation Theme team also identified challenges that need to be overcome to advance the implementation of collaborative research. The team recognised the challenges associated with having limited resources (time and funding) to support and engage a collaborative research team throughout the research process. The lack of diversity and representation within the team was also an identified challenge. Theme team members reflected on the need to seek members who bring more diverse experiences than we currently have related to gender, age (particularly young people with cerebral palsy), culture, and living situation. To achieve greater diversity within collaborative research teams, the CP-ACHIEVE team is building resources to support inclusion of people with disability with additional support needs such as interpreters and other communication supports, or research development training support. The aim of these additional resources is to create welcoming and relevant research contexts for consumers bringing diverse experiences and views.

Strengths and limitations

The partnership among parents, young people with lived experience and clinical researchers in the work of CP-ACHIEVE and the conduct of this reflective review is a strength of this research, our team, and the CP-ACHIEVE research program. Our collective experiences enables us to provide real world examples and recommendations for other groups, organisations and research teams to consider, to ensure informed participatory research is standard practice, new opportunities are embraced, and learning is enhanced for everyone. Limitations of our work include the lack of involvement of consumers aged 10-20 years with cerebral palsy and that our team is predominantly female. Our co-researchers with lived experience are working with the broader CP-ACHIEVE research team to increase the diversity of lived experience within individual research projects. The broad age range of our group has been a strength, supporting consideration of life-course perspectives in our research discussions and decisions. The self-reflective approach taken could be seen as a research limitation – perhaps our review should have been undertaken by an independent observer. However, we have committed to learn together, and the approach taken in this paper is consistent with that commitment. In addition to this descriptive exploration, CP-ACHIEVE has a funded doctoral student who is undertaking formal evaluations of the process, authenticity, impact and resource use related to consumer involvement across the program.

Implications for practice and research

The CP-ACHIEVE framework is novel and provides many opportunities for generating evidence to support clinical practice, education, policy making and research. Involvement of people with lived experience has been recognised as an essential requirement for medical research grant applications however should be conducted with true intent and meaningful collaboration (NHMRC, 2016). Implications of a collaborative approach should firstly be recognition of the value of all participants which includes having funding, appropriate resources and environments to collaborate, and agreed upon roles and responsibilities. Information developed and what is learned when working within a new model should be shared widely. Organisations should be encouraged to partner and share resources to learn from each other and engage with diverse groups and people e.g., cerebral palsy registers, Disability Organisations, Health Promotion organisations, community groups, policy makers. Collaborating widely in research has the potential to increase the power of studies through effective engagement, enable more diversity through greater reach, and enhance the potential for, and feasibility of, multi-site and longitudinal research. When aiming for collaborative research, participation questions needing to be addressed include:

- How to make it possible for people with lived experience/parents/community partners to be present at each research phase? (attendance) and
- How to make it possible for people with lived experience/parents/community partners to be involved at each research phase? (involvement).

Barriers of lack of time and funding, and problems with lack of diversity were identified by our team and should be targeted in research. The voices of those who are seldom heard should be identified early. Strategies inclusive of diversity in gender, ability, culture, low resourced and those who have disengaged with services need to be developed. Having people with disability at all stages of the research process: recruiters, key contact persons, leading research, and disseminating findings, across diverse communities and settings may provide role models and promote involvement. Further ideas to increase involvement, include running “Town Hall’ sessions (in person or online) for information sharing and feedback in a general forum where everyone is welcome.

Successful involvement should always consider the family and carers supporting young people with disabilities. Inclusion of their voice was considered essential by our team. Parents and family members have a different kind of ‘lived experience’ of disability to the young people, and so bring another set of perspectives to the table. Family members can support the young person with lived experience, if needed, to contribute directly through encouragement, preparation for meetings, and communication support. Family members may need to speak on behalf of a person with cerebral palsy who finds it difficult to 'speak' for themselves (using any form of communication) to ensure their voice and perspective is represented. In addition, family members advocating on behalf of people with severe and profound disability are needed to ensure the needs of this group are also considered.

Research should promote and celebrate inclusive and diverse involvement and collaboration within teams. Information, provided through regularly updated and co-authored documents, fact sheets and/or newsletters, about how people with lived experience can, and do, contribute could be used to highlight opportunities and contributions of all team members. Consideration of how people with lived experience work together and best strategies to structure collaboration should be determined jointly.

Key recommendations for authentic and effective involvement

- Recognition of the inherent importance and value of including people with lived experience of disability in the research team *"Nothing about us without us"*
- Discussion and planning with respect to the format of meetings – e.g., in person or online; length of meetings; realistic agendas that allow time for attendees to prepare and contribute. Alongside this, ensuring preparation materials for meetings or projects take account of the different cognitive, communication and experience of researchers.
- Inclusion of funding to pay people not already employed by partnering institutions to be paid for their time and contribution.
- Mentorship and encouragement of people wanting to contribute but lack experience and/or confidence to do so.
- Explicit invitations to contribute to discussions and overt demonstration of the value of diverse contributions within meetings and activities.
- Ensure regular communication and updates with information about how consumers can be involved as research progresses, along with information about activity happening in other projects so they can connect and contribute
- Parents (especially those who parent younger children with disability) as well as those from hard-to-reach groups, need to be firstly consulted and then briefed on the research being conducted as well as throughout the research phases putting them at ease and helping them to feel both confident and comfortable letting their child have their voice and contributions heard. This may ensure that younger people with lived experience can be more active in the research providing a better cross-section of consumer priorities and experiences.

Conclusions

From inception, CP-ACHIEVE has committed to co-research and collaboration with young people with cerebral palsy (10 to 30 years of age) and their families. While there is more work to do, the reflective process undertaken by the Participation Theme team highlights the positive steps CP-ACHIEVE has taken to ensure consumer participation in research. We have learned together and created ways of working together to support both attendance and involvement in each step of the research cycle. While we still have much more to learn, we offer this knowledge and our experiences to assist other research teams in their journeys towards collaborative research alongside people with lived experience of disability.

Author's Note

The authoring group comprises the CP-ACHIEVE Participation Theme research team. CP-ACHIEVE stands for the Australian Centre for Health, Independence, Economic participation and Value Enhanced care for adolescents and young adults (10-30 years) with Cerebral Palsy. It is an Australian National Health and Medical Research Council funded Centre of Research excellence. The team includes young people with cerebral palsy, parents of young people with cerebral palsy and health professional researchers in the fields of occupational therapy, physiotherapy, social work, psychology, and medicine. We work across settings of health, disability, education, and the community. We are from different states of Australia, New Zealand and Sweden.

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ORCID iDs

Gaela Kilgour https://orcid.org/0000-0002-8867-7782
Alesia Lu https://orcid.org/0009-0009-4127-3404
Nicole Kozelj https://orcid.org/0009-0009-2334-8839
Jane Tracy https://orcid.org/0000-0002-4070-8615
Lyndal Hickey https://orcid.org/0000-0001-6418-4935
Mats Granlund https://orcid.org/0000-0002-6894-9816
Nora Shields https://orcid.org/0000-0002-6840-2378

Prue Morgan https://orcid.org/0000-0002-2573-6562
Gabrielle Drake https://orcid.org/0000-0002-5237-0762
Stacey Cleary https://orcid.org/0000-0002-7378-5457
Christine Imms https://orcid.org/0000-0001-9055-3554

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