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SCOPING REVIEW

Involving people with lived experience when setting cerebral palsy research priorities: A scoping review

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Abstract

Aim: To describe research priority-setting activities for cerebral palsy (CP) that have been conducted worldwide involving people with lived experience, focusing on participant characteristics, methods employed, identified research priorities, and collaboration as research partners.

Method: The JBI scoping review approach was followed. Six electronic databases and grey literature were searched for all publications up to February 2024. We extracted study and participant characteristics, methods, and research priorities. Priorities were then categorized into prevention and cure, quality of life and community engagement, and service provision and intervention.

Results: Five studies from North America and Australia met the inclusion criteria. Participants with lived experience were most often parents/caregivers ($n = 135$, proportion 12–80%), with 54 (proportion 12–25%) people with CP participating in the priority-setting exercises. The studies' methods were varied, with surveys and workshops being the most common. The most reported category of research priorities was optimal intervention. People with lived experience collaborated as research partners (e.g. in aspects of study development/analysis/reporting) in four studies.

Interpretation: This review, the first to examine CP research priority-setting efforts on a global scale, identified five activities conducted to date. The small overall number of participants with lived experience of CP, originating only from North America and Australia, highlights the need for increased representation to better reflect the diverse CP community worldwide. Future projects need to address these gaps, using rigorous methodologies, and continued collaboration with research partners to ensure their perspectives shape and enhance the research agenda.

Cerebral palsy (CP) describes a group of non-progressive, lifelong neurological disorders of movement and posture, resulting from injury to the developing brain.[1] CP is a heterogeneous condition, with variation in prevalence, aetiology, and clinical presentation across and within geographic contexts. Management of CP involves tailored multidisciplinary care to address the diverse individual goals of function, participation, and reducing secondary impairments.[2]

In recent decades, research and publications in the CP field have steadily increased.[3,4] Historically, decision-making in health research was driven by research investigators.[5] Research priority setting, which has become more common since the late 2000s, involves activities that allow stakeholders to identify, prioritize, and reach consensus on areas, topics, or questions that need to be addressed by research.[6] Research priority setting with relevant stakeholders helps ensure that research addresses critical evidence gaps focusing on high-priority areas (reducing 'research waste'), promotes accountability in research, enhances the relevance, uptake, and translation

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of research evidence, and thereby improves health outcomes.[5–7] Stakeholder groups may include medical and allied health professionals, policy-makers, government and non-government organizations, funders, and people with lived experience (people with the condition and their family/caregivers, also known as patients, consumers, community).[5–7] A 2021 scoping review reported that 30% of 731 research priority-setting projects included people with lived experience as participants in the priority-setting exercises, such as surveys and focus groups.[6]

Moreover, recognition of the benefits of including people with lived experience in health research has led to the evolution of their role from solely as study participants to collaborative and active research partners, also known as coproducers or coinvestigators. This is now strongly encouraged by key groups in countries including the UK (Involve),[8] Australia (National Health and Medical Research Council),[7] and the USA (Patient-Centred Outcomes Research Institute),[9] as well as by CP-specific groups,[10] and publications including *Developmental Medicine & Child Neurology*.[11] In the 2021 scoping review described above, a smaller proportion of studies (17%) included people with lived experience more actively in the project such as on advisory boards or codeveloping project materials (research partners).[6]

The first research priority-setting project with people with lived experience of CP was published in 2010. This Australian study additionally reported a comparison between the priorities of people with lived experience, and those of researchers and clinicians.[12] Half of the priorities identified by people with lived experience were not identified by the researchers and clinicians, confirming the importance of lived experience in priority setting. Since then, CP priority-setting activities have been conducted elsewhere in the world, along with extensive research activities in the field. To appropriately guide new research and direct funding going forward, it is imperative to understand the landscape of priority setting with people with CP to date. This includes identifying what priority setting has been conducted (within and beyond published research) and whether it represents people with CP across the globe, and their diverse presentations, as well as what research priorities have been set.

As a first step, this scoping review aims to describe CP research priority-setting activities that have been conducted with people with lived experience, focusing on their participation and collaboration as research partners. Our research question is: 'What priority setting for CP research has been conducted globally with people with lived experience?' We will address this overarching question through four sub-questions: (1) What are the characteristics of people with lived experience who have participated in the priority-setting studies/projects? (2) What methods have been employed to set research priorities? (3) What categories of research priorities and questions have been identified? (4) How have people with lived experience collaborated as research partners in priority-setting studies/projects?

What this paper adds

- This scoping review systematically identified that five research priority setting projects have been conducted with people with lived experience of cerebral palsy (CP).
- Projects have been conducted in North America and Australia, using varied methodologies.
- Parents/caregivers have participated in priority setting more often than people with CP.
- Four of five studies involved people with lived experience as research partners.
- Gaps in research priority-setting activities were identified, to inform future projects.

METHOD

To identify and review CP research priority setting involving people with lived experience, we employed a scoping review methodology adhering to the JBI approach.[13] This methodology enabled us to systematically explore a wide range of evidence on this topic, including non-empirical sources. The study protocol for this review was completed following the JBI template and registered on the Open Science Framework.[14] The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist was used for reporting (Appendix S1).[15]

Search strategy

We searched Ovid MEDLINE (1946–present), Ovid EMBASE, CINAHL, Web of Science ('core collection'), SCOPUS, and Global Index Medicus for all publications to 1st February 2024. Search terms were developed in consultation with an academic librarian. We used keywords and subject headings for 'cerebral palsy' and 'research priorities/agenda', including truncations, and adapted these for each database (Appendix S2). We also screened the reference lists of included papers for relevant studies. Because of the broad nature of the research question, we additionally conducted grey literature searches to identify findings from priority-setting activities outside of peer-reviewed literature, such as reports and web-based material. This grey literature search included websites of known priority-setting organizations, including the James Lind Alliance (https://www.jla.nihr.ac.ul/) and the worldwide research priority-setting database (https://ois.lbg.ac.at/priority-setting-database/). Google and Google Scholar were also searched for grey literature using the terms 'cerebral palsy' AND 'research priority' as per consultation with an academic librarian. To account for the use of English search terms, we individually searched for priority-setting activities within websites of known CP organizations in other languages, using Google Translate.

TABLE 1 Characteristics of included studies.

Citation	Source	Country	Driving body	Partnership with people with lived experience within study
Garrity et al.[23]	Online poster	Australia	Cerebral Palsy Alliance	Lead author is a person with CP
Gilbert et al.[21]	Published literature	USA	CP Research Network (CPRN)	Parents/caregivers were co-authors
Gross et al.[20]	Published literature	USA	CP Research Network (CPRN)	Research leadership team included two people with lived experience
Lungu et al.[22]	Published workshop report	USA	NINDS	Parents/caregivers were co-authors
McIntyre et al.[12]	Published literature	Australia	Cerebral Palsy Alliance	No

Abbreviation: CP, cerebral palsy.

Eligibility criteria

Following the JBI population, concept, context approach,[13] our inclusion criteria were original priority-setting exercises of any design that identified CP research priorities (concept) with people with lived experience, specifically people with CP and/or their families and caregivers (population) (Appendix S3). Both published and grey literature sources were considered. We included studies with mixed participant groups (e.g. researchers and clinicians), provided they also included people with lived experience. There was no minimum requirement for the proportion of participants with lived experience. Limits were not placed on country, language, or year of publication to capture a wide range of priority-setting activities (context). Studies that described research priorities for conditions or disorders that were not exclusively CP, such as 'chronic illness'[16] or 'neurodisability',[17] were excluded.

Evidence screening and inclusion

Potential records were exported from each database into EndNote and uploaded on Covidence, a web-based collaboration software platform for abstract screening, full-text review, and data extraction.[18] Duplicates were removed in Covidence. Two independent reviewers (EY and SG) conducted title and abstract screening of the studies using the eligibility criteria. The same reviewers then independently reviewed the full-text records to confirm if they met the inclusion criteria. Consensus regarding the records for inclusion was reached through discussion.

Data extraction

A data extraction tool was developed and built in Covidence and piloted by two reviewers (Appendix S4). Extracted data included study characteristics, such as year of publication, source type, funding bodies, and whether the project involved people with lived experience as research partners. Characteristics of people with lived experience that participated were extracted where reported, including age, sex, motor severity of CP, cultural and linguistic diversity, urban/regional/remote residence, and any other relevant data. The overall study design as well as the methods for determining the conceptual and final research priorities were extracted. The top research priorities or themes from each study were also identified. Two independent reviewers conducted data extraction, and discrepancies were resolved through discussion. Critical appraisal of individual sources of evidence or risk of bias assessment of individual sources was not performed, in accordance with the JBI guidelines.[19]

Data analysis and synthesis

Descriptive analysis of the extracted data was conducted with presentation in tabular and graphical formats. This included frequency counts and proportions of study characteristics, methods, participant numbers (by type and characteristics), and involvement of people with lived experience as research partners. The research priorities/questions reported in each study were categorized into three groups using a modification of McIntyre et al.[12] categories, because of the breadth of topics covered: (1) cause and prevention, (2) community participation and quality of life, (3) optimal intervention. Each research priority was then subcategorized based on keywords and displayed graphically.

RESULTS

Search results and study selection

The database search strategy (Appendix S2) identified 320 records (Figure S1). After removal of duplicates and screening of titles and abstracts, 45 records were included for full-text review. Among these, three were not original research articles and 21 did not set priorities for research. Others were excluded because they conducted research priority setting that was not specific to CP ($n = 15$), such as 'neurodisability' or 'neurological impairment', or did not include people with lived experience, despite being CP-focused ($n = 1$). Four published studies met the inclusion criteria for this review, and one additional priority-setting exercise was identified

TABLE 2 Included studies—participant characteristics and methods.

	Studies reporting item (*n*)	Participants *n* (%)
Type of participants	4	
People with CP		54 (12)
Parents/caregivers of people with CP		135 (31)
Other stakeholders including clinicians, researchers, advocates		252 (57)
Average age of person with CP	2[a]	46 years
Average age of person with CP represented by caregiver	2[b]	12 years
Motor severity of CP (GMFCS level)	2[c]	
GMFCS level I–III		72 (51)
GMFCS level IV–V		64 (46)
Not reported		4 (3)
Method(s) used	5	
Survey	4	
Workshop	2	
Webinar	2	
Conceptual priorities defined by people with lived experience		
Yes	4	
Not reported	1	
Final priorities refined by people with lived experience		
Yes	3	
No	2	

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

[a] Gilbert et al.[21]: average age of community participants with CP; Gross et al.[20]: average age of codigital participants with CP.

[b] Gilbert et al.[21]: average age of people with CP represented by a parent/caregiver; Gross et al.[20]: average age of codigital participants with CP represented by a parent/caregiver.

[c] Gilbert et al.[21]: GMFCS level of voting community participants; Gross et al.[20]: GMFCS level of codigital participants (both people with CP that participated and those represented by parents/caregivers).

and included from the grey literature search. In total, five CP priority-setting studies involving people with lived experience were identified and included.

Study characteristics

The five included studies were published between 2010 and 2022 (Table 1). Three were original research articles,[12,20,21] one was a report detailing a priority-setting workshop,[22] and one was a priority-setting exercise from the grey literature search.[23] All five studies were conducted in high-income countries, with three in North America,[22–22] and two in Australia.[12,23]

There were three major bodies driving the five studies, all of which are CP-focused: the CP Research Network (USA), the National Institute of Neurological Disorders and Stroke (USA), and Cerebral Palsy Alliance (Australia). Funding sources for the studies included both government and non-government funding agencies. Four studies were not limited to a specific motor type of CP, while the fifth study focused on research priorities for dystonic CP only (Table 2).[21]

Study participants

Types of participants

The total number of participants was greater than 541 (Figure 1) (one study did not report the numbers of participants).[22] The specific types of participants varied across studies (Figure 1, Table 2). Participants with lived experience included people with CP and parents/caregivers of people with CP. While one study exclusively included people with lived experience,[23] across all five studies, a greater number of parents/caregivers were involved in priority development or prioritization stages than people with CP. Of the four studies that described their participants, there was a total of 54 (12%) participants with CP (within each study, range 5–33 participants) and 135 (31%) parent/caregiver participants (range 15–72 participants), with a total of 189 (43%) participants with lived experience. As demonstrated in Figure 1, the proportion of participants that were parents/caregivers ranged from 12% to 80% across the five studies, while participants with CP ranged from 4% to 25%. In addition to people with lived experience, the other participants were most commonly researchers and health care professionals in CP, with 252 (57%) other participants involved. Two of the studies reported the inclusion of a greater proportion of 'other' participants than participants with lived experience, and overall, this category had the greatest degree of variation, ranging from 0% to 84%.[12,21]

Participants with lived experience

Three of the studies provided some information about their participants with lived experience (Table 2).[12,20,21] The average reported age of people with CP was mid-40s, while amongst the children with CP represented by their parents and caregivers the average age was 14 years (two studies).[20,21] Three studies reported the motor severity of participants with CP pooled with children with CP represented by their parents, as classified by the Gross Motor Function Classification System (GMFCS),[12,20,21] all included participants at each of the five GMFCS levels. No studies specified the sex of participants, whether they had intellectual impairment or epilepsy, or used augmentative and alternative communication, or were from culturally and linguistically diverse backgrounds.

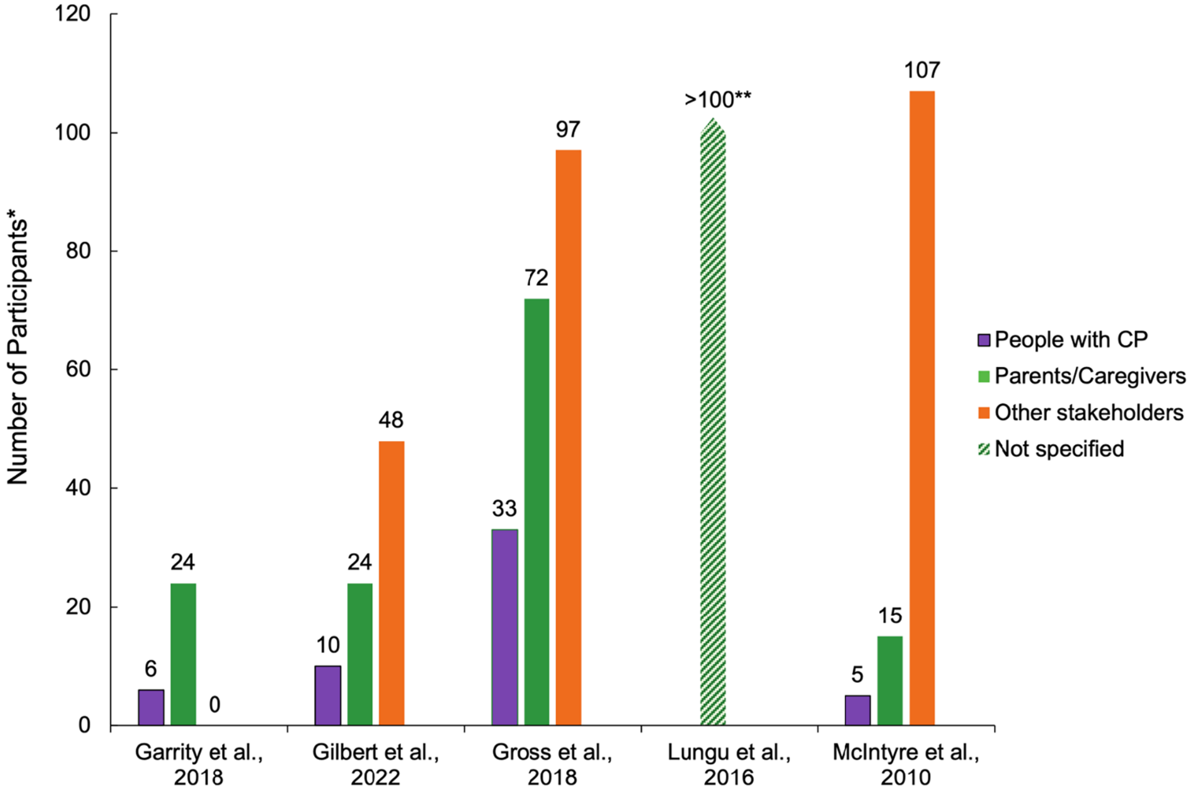

FIGURE 1 Number of participants in cerebral palsy (CP) research priority-setting studies that are people with CP, parents/caregivers of people with CP, or participants without lived experience. [a]Data includes the largest number of participants represented at any priority development or prioritization stage. Gross et al.[20] included 38 people with CP, 99 parents/caregivers, and 138 other participants in an initial webinar. Gilbert et al.[21] also included 20 people with CP, 39 parents/caregivers, and 107 other participants who viewed two of the three webinars delivered.
[b]Lungu et al.[22] reported >100 participants but the breakdown of participants is unknown.

Priority-setting methods

The included studies used a range of study designs to identify research priorities, primarily surveys and workshops (Table 2). The grey literature source conducted a single survey to identify CP research priorities.[23] McIntyre et al.[12] conducted a three-round Delphi survey to identify and then further prioritize topics. Gilbert et al.[21] arranged an online three-part webinar series before conducting two surveys, one to identify research uncertainties and one to prioritize the uncertainties. Gross et al.[20] prepared five online webinars followed by a codigital survey to generate and rank the research ideas and an in-person workshop to further identify the highest-priority ideas. Lungu et al.[22] organized a single in-person workshop with an agenda to discuss the research gaps in CP treatment.

Various methods were used to develop the conceptual research priorities within each study, as well as to identify the final list of priorities (Table 2). Four studies elicited initial, or 'conceptual', research priorities from people with lived experience using surveys.[12,20,21,23] Among these, the investigators in Gilbert et al.[21] and Gross et al.[20] arranged webinars to educate participants on the current state of CP research before asking participants to complete the initial survey. The fifth study did not report how initial priorities were conceptualized.[22] The final method for devising initial priorities was evidenced in McIntyre et al.,[12] who conducted a literature review to generate initial research questions in the arms of the survey series that did not include people with lived experience. Three studies (60%) involved people with lived experience of CP to refine the finalized list of research priorities.

Identified research priorities

Four studies reported research priorities, ideas, questions, or uncertainties, while the fifth described priority topic areas.[22] The number of individual CP research priorities reported in the five studies ranged from 7 to 38 (total 109). Three studies ranked the research priorities/themes as part of the methodology.[12,20,21] Using the modified McIntyre categories, the most common research priority category was optimal intervention (61%), followed by community participation and quality of life (30%), and cause and prevention (9%) (Figure 2, Appendix S5). Three studies reported priorities across all three categories; the remaining two studies reported priorities in two categories. McIntyre et al. ranked CP prevention as the top research priority, despite there being fewer individual questions in

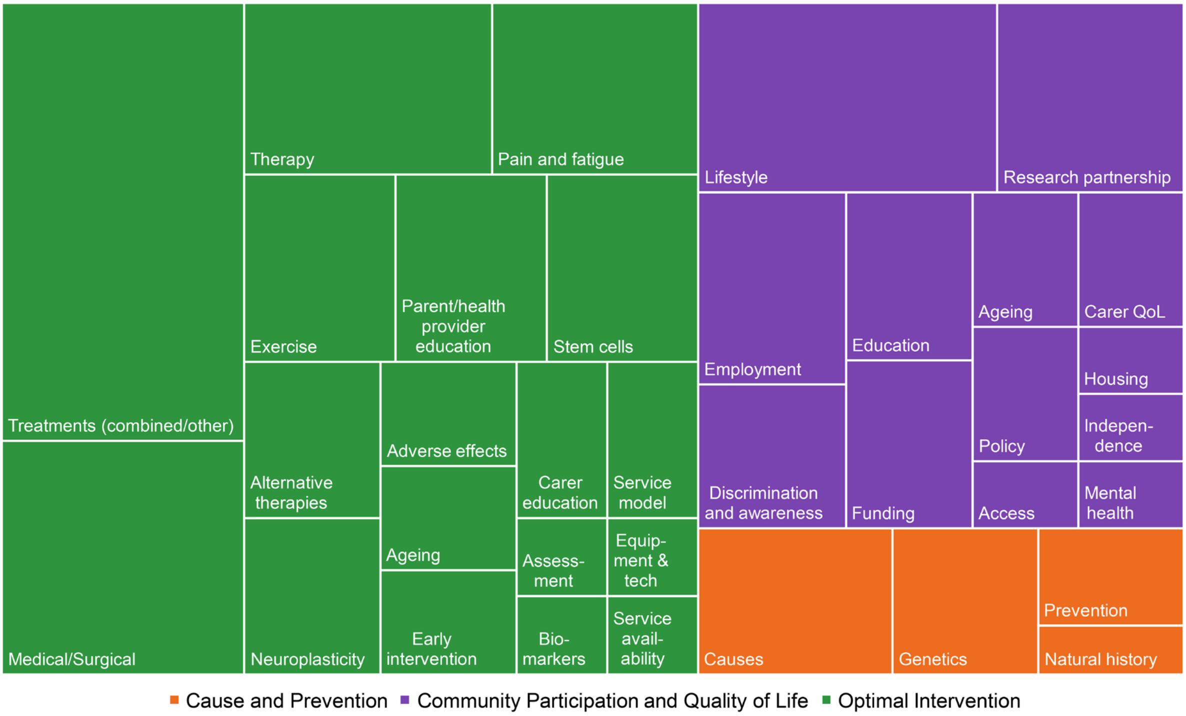

FIGURE 2 Categorization of research priorities reported in the literature. Abbreviation: QoL, quality of life.

this category ($n = 4$ of 23 priorities).[12] The grey literature source, which involved exclusively consumer participants, identified most priorities in the community participation and quality of life category.[23]

Partnership with people with lived experience

Four of the five studies included people with lived experience as research partners conducting or overseeing the study (Table 2).[20–23] In two studies, research partners (at least two parents of people with CP) were involved via a leadership team,[20,21] who collaborated at all stages of the study from recruitment to data analysis.[22] Parents of people with CP were named coinvestigators on three studies,[20–22] while a person with CP was named a coinvestigator on one study, completing data analysis and interpretation.[23] The final study did not include people with lived experience as research partners.[12]

DISCUSSION

This scoping review provides a novel depiction of CP research priority-setting activities conducted globally with people with lived experience to date. We identified five relevant studies, and synthesized the methods employed, the characteristics of participants with lived experience involved, the most reported research priorities, and the extent of research partnerships with people with lived experience.

It was encouraging to identify five studies, including 189 participants with lived experience in North America and Australia, that used comprehensive methods to glean the research priorities of people with lived experience of CP. These priorities are being used to shape the research agenda,[24,25] direct funding,[26] and ensure research being conducted meets the priorities of these key stakeholders. Yet we propose that further research priority setting is required, to better reflect the views of the millions of people living with CP globally. New projects should be considered to complement the existing evidence on research priorities, including: (1) *Participants with lived experience of CP in other countries, particularly low- and middle-income countries*. An estimated 85% of children with disabilities reside in low- and middle-income countries,[27] and context will inevitably influence research priorities identified. It is expected that priorities of people with CP will be influenced by factors including availability and access to services and interventions; national disability support and policy; and prevailing causal factors of CP. Encouragingly, CP research priority setting has already been conducted with health care professionals from 22 countries in Africa.[28] Additional projects involving people with lived experience, as well as engaging people in new geographic contexts, is essential. (2) *Greater participation of people with CP across the lifespan*. The studies to date, and similar priority-setting projects for neurological impairment and childhood disability,[16,17,29–31] have involved a higher proportion of parents/caregivers than people with CP. Viewpoints may differ between these participant groups. There is also a gap in research priority setting with children and young adults with CP. Identifying the perspectives of people with CP throughout the lifespan will add a unique and invaluable dimension to this field. (3)

Participation of people with differing presentations of CP. In particular, a focus on including participants who use a wheelchair for mobility, use augmentative and alternative communication, have an intellectual impairment, or have high support needs. This will ensure that the heterogeneity of CP is represented in research prioritization. It is essential to offer accessible participation to ensure that all potential participants are supported to participate. Consistent reporting of participants' GMFCS levels, presence/severity of associated impairments, and use of assistive technology will facilitate interpretation of priorities identified in future projects. (4) *Participants with diverse backgrounds*. Studies to date described few participants with diverse backgrounds such as cultural and linguistic diversity, rural or regional residence, or Indigenous peoples. These important factors likely influence research priorities, and the voices of participants with diverse backgrounds should be amplified.

Heterogeneous methodologies were used in the five studies, a common finding in health research priority setting.[6,32,33] As this field continues to grow, more rigorous methods and reporting guidelines for conducting priority-setting research involving people with lived experience have been proposed. For example, the James Lind Alliance[34] promotes the equal involvement of people with lived experience and clinicians in research priority setting, and offers comprehensive guidelines on their methodology.[17] Future projects may also consider the use of specific reporting guidelines for (1) priority setting, and (2) involving people with lived experience in health research, to facilitate transparency and quality of research.[5,35]

The most common research priorities identified in this review were related to optimal intervention. It is understandable that people with lived experience prioritize research that has the potential to directly benefit them. However variation existed between the studies; for example, McIntyre et al. found the highest ranked questions to be ‘How can CP be prevented?’ (followed by ‘What are the optimal treatments for CP?’).[12] New priority-setting projects should be mindful of, and transparent about, any potential influence of their methods on outcomes, particularly during the generation of conceptual priorities. The James Lind Alliance guidelines specifically recommend gathering conceptual priorities from a wide range of contributors, to ensure a balanced and unbiased representation of people with lived experience and other participants.[34] Finally, explicitly describing the consensus between research priorities identified by different stakeholder groups,[12] or including consensus within the methodology,[20,21] is an important step in establishing a balanced representation of all perspectives.

People with lived experience were actively involved as research partners in four of the five studies, in accordance with recommendations.[7,9] Moving forward, researchers should ensure that new study teams include research partners with lived experience of CP. Particular consideration may be given to those who may traditionally be underrepresented, such as people using augmentative and alternative communication, with an intellectual impairment, or living remotely. Additionally, children and young people with disabilities are underrepresented as research partners.[30,36] A recent Canadian study involving young people with neurodevelopmental disabilities (including CP) identified training needs for engaging young people as research partners.[36] Their recommendations included effective communication, building team rapport, and considering multiple methods for research training. Other strategies to improve partnership with people with lived experience include adequate planning and financial investment to offer compensation, and the development of good relationships.[36,37] Fortunately, many toolkits and resources are available to help guide new projects.[34,37–40] Of note for low- and middle-income countries, one of these guides has recently been translated into Brazilian Portuguese.[41]

Limitations

Our search strategy and eligibility criteria intentionally limited our scope to CP-specific priority-setting studies. This resulted in the exclusion of priority-setting projects for related conditions, such as neurodisability,[17,31,42,43] childhood chronic illness,[16] childhood lower limb conditions,[44] and augmentative and alternative communication.[45] It remains possible that some of these studies included people with lived experience of CP as participants . Future studies should consider the priorities identified in these ‘CP-adjacent’ fields and whether their findings could complement the CP-specific priority-setting activities. We acknowledge that grey literature searching is non-systematic, and CP priority-setting exercises outside of indexed journals may have inadvertently been overlooked. However, we conducted a broad grey literature search, including individual websites of known CP organizations not in English, to mitigate this risk. We encourage caution with any generalization of the research priorities identified in this review, given the small number of included studies, which originated from two high-income countries only. Furthermore, a detailed examination of the research priorities and questions reported, and whether these have been adequately answered with research, was outside the scope of this review. This should be conducted, with the aims of (1) identifying persisting research gaps and (2) recommending enhanced translation efforts for any research questions that have been answered but continue to be identified as a priority.

Conclusion

This scoping review has described, for the first time, the research priority setting for CP that has been conducted worldwide with people with lived experience. Comprehensive activities have been conducted and report research priorities in North America and Australia. Our findings particularly emphasize the need for increased representation of individuals with CP and of people with lived experience in low- and middle-income countries in new priority-setting projects, to ensure the research agenda adequately reflects the perspectives of the diverse global CP community and context. Ultimately, by setting a research agenda that appropriately reflects the broader CP community, CP research is likely to have more meaningful impacts on the lived experience of individuals with CP and their families.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available in supporting online information and included published studies.

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REFERENCES

1. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl 2007; 109: 8–14.
2. Bekteshi S, Monbaliu E, McIntyre S, et al. Towards functional improvement of motor disorders associated with cerebral palsy. Lancet Neurol 2023; 22: 229–43.
3. Wang X, Teh SH, Wang XH. Knowledge mapping of spastic cerebral palsy. A bibliometric analysis of global research (2000-2022). Ital J Pediatr 2024; 50: 9.
4. Danis A, Kutluk MG. The evolution of cerebral palsy publications and global productivity: a bibliometric analysis between 1980 and 2019. Acta Neurol Belg 2021; 121: 1807–14.
5. Tong A, Synnot A, Crowe S, et al. Reporting guideline for priority setting of health research (REPRISE). BMC Med Res Methodol 2019; 19: 243.
6. Grill C. Involving stakeholders in research priority setting: a scoping review. Res Involv Engagem 2021; 7: 75.
7. NHMRC. Statement on Consumer and Community Involvement in Health and Medical Research. National Health and Medical Research Council; 2016.
8. Involve. https://www.involve.org.uk/ (accessed 12 February 2024).
9. Patient-Centred Outcomes Research Institute. https://www.pcori.org/ (accessed 12 February 2024).
10. Thomas SP, Novak I, Ritterband-Rosenbaum A, et al. The critical need to accelerate cerebral palsy research with consumer engagement, global networks, and adaptive designs. J Pediatr Rehabil Med 2024; 17: 9–17.
11. Dan B. Individuals with lived experience of disability should participate in every stage of research. Dev Med Child Neurol 2023; 65: 4–5.
12. McIntyre S, Novak I, Cusick A. Consensus research priorities for cerebral palsy: a Delphi survey of consumers, researchers, and clinicians. Dev Med Child Neurol 2010; 52: 270–5.
13. Peters MDJ, Marnie C, Tricco AC, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth 2020; 18: 2119–26.
14. Younan E, McIntyre S, Garrity N, et al. Setting Priorities for Cerebral Palsy Research with Consumers: A Scoping Review Protocol. https://osf.io/58szj/ (accessed 8 February, 2024).
15. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med 2018; 169: 467–73.
16. von Scheven E, Nahal BK, Cohen IC, et al. Research Questions that Matter to Us: priorities of young people with chronic illnesses and their caregivers. Pediatric Research 2021; 89: 1659–63.
17. Morris C, Simkiss D, Busk M, et al. Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership. BMJ Open 2015; 5: e006233.
18. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. (https://www.covidence.org.).
19. JBI Scoping Review Network Resources. https://jbi.global/scoping-review-network/resources (accessed 23 May 2023).
20. Gross PH, Bailes AF, Horn SD, et al. Setting a patient-centered research agenda for cerebral palsy: a participatory action research initiative. Dev Med Child Neurol 2018; 60: 1278–84.
21. Gilbert LA, Fehlings DL, Gross P, et al. Top 10 Research Themes for Dystonia in Cerebral Palsy: A Community-Driven Research Agenda. Neurology 2022; 98: 237–45.
22. Lungu C, Hirtz D, Damiano D, et al. Report of a workshop on research gaps in the treatment of cerebral palsy. Neurology 2016; 87: 1293–8.
23. Garrity N, Balde I, McIntyre S. CP Quest Research Priorities. https://cerebralpalsy.org.au/get-involved-research/cp-quest/ (accessed 23 May 2023).
24. CPRN. Cerebral Palsy Research. https://cprn.org/research/cerebral-palsy-research/ (accessed 12 February 2024).
25. The Australia and New Zealand Cerebral Palsy Strategy. https://cerebralpalsystrategy.com.au/wp-content/uploads/2020/03/CP-Strategy-BOOKLET-2020_WEB_FINAL_V2.pdf (accessed 23 May 2023).
26. CPA Research Foundation https://cerebralpalsy.org.au/research-foundation/).
27. Khandaker G, Smithers-Sheedy H, Islam J, et al. Bangladesh Cerebral Palsy Register (BCPR): a pilot study to develop a national cerebral palsy (CP) register with surveillance of children for CP. BMC Neurol 2015; 15: 173.
28. Donald KA, Kakooza AM, Wammanda RD, et al. Pediatric Cerebral Palsy in Africa: Where Are We? J Child Neurol 2015; 30: 963–71.
29. Odgers HL, Tong A, Lopez-Vargas P, et al. Research priority setting in childhood chronic disease: a systematic review. Arch Dis Child 2018; 103: 942–51.
30. Njelesani J, Mlambo V, Denekew T, et al. Inclusion of children with disabilities in qualitative health research: A scoping review. PLoS One 2022; 17: e0273784.
31. Diskin C, Malik K, Gill PJ, et al. Research priorities for children with neurological impairment and medical complexity in high-income countries. Dev Med Child Neurol 2022; 64: 200–8.
32. Bourne AM, Johnston RV, Cyril S, et al. Scoping review of priority setting of research topics for musculoskeletal conditions. BMJ Open 2018; 8: e023962.

33. Crilly J, Huang YL, Krahe M, et al. Research priority setting in emergency care: A scoping review. J Am Coll Emerg Physicians Open 2022; 3: e12852.
34. James Lind Alliance. The James Lind Alliance Guidebook. https://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-10-March-2021.pdf (accessed 16 July 2023).
35. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ 2017; 358: j3453.
36. Dong SY, Nguyen L, Cross A, et al. Youth engagement in research: exploring training needs of youth with neurodevelopmental disabilities. Res Involv Engagem 2023; 9: 50.
37. NHMRC. Toolkit for Consumer and Community Involvement in Health and Medical Research. https://www.nhmrc.gov.au/about-us/consumer-and-community-involvement/consumer-and-community-engagement (accessed 23 May 2023).
38. Oliver S, Clarke-Jones L, Rees R, et al. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. Health Technol Assess 2004; 8: 1–148.
39. Walsh M, Harman I, Manning P, et al. Including People Who Use Augmentative and Alternative Communication in Qualitative Research: Can You Hear Us? International Journal of Qualitative Methods 2024; 23: 1-–13.
40. Smits D-W, Van Meeteren K, Klem M, et al. Designing a tool to support patient and public involvement in research projects: the Involvement Matrix. Research Involvement and Engagement 2020; 6: 30.
41. Jesus CCDAF, Brugnaro BH, Campos ACD, et al. Translation of the Involvement Matrix tool into Brazilian Portuguese. Fisioterapia em Movimento 2023; 36: e36130.
42. Nederland C. Research Agenda for Child Rehabilitation: The 12 most important questions from parents to researchers. https://cpnederland.nl/wat-doet-cp-nederland/projecten/onderzoeksagenda-kinderrevalidatie/ (accessed 20 June 2023).
43. Cross H, Lim M. The Top Ten UK research priorities for interventions in childhood neurological disorders. https://www.jla.nihr.ac.uk/priority-setting-partnerships/childhood-neurological-conditions/downloads/Childhood-Neurological-Conditions-PSP-Final-Report.pdf (accessed 26 May 2023).
44. Vella-Baldacchino M, Perry DC, Roposch A, et al. Research priorities in children requiring elective surgery for conditions affecting the lower limbs: a James Lind Alliance Priority Setting Partnership. BMJ Open 2019; 9: e033233.
45. O'Keefe BM, Kozak NB, Schuller R. Research priorities in augmentative and alternative communication as identified by people who use AAC and their facilitators. AAC: Augmentative & Alternative Communication 2007; 23: 89–96.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.

Appendix S2: Search strategy.

Appendix S3: Inclusion criteria for studies (Population, Concept, Context).

Appendix S4: Novel data extraction tool.

Appendix S5: Categorization of research priorities reported in each study.

Figure S1: Reporting of Items for Systematic Reviews and Meta-Analysis—Extension for Scoping Reviews selection of sources of evidence flow diagram.

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