

Answering the call: co-designing a global trials network for cerebral palsy

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People with cerebral palsy (CP) demand more timely research delivering results.¹ The discovery of new treatments takes decades and costs millions of dollars,² and the translation into usual care takes time and effort from clinicians. The pace of research feels too slow for people with CP, where timely intervention prevents significant complications. With over 20 million affected globally, CP, the world's most common lifelong physical disability, presents substantial unmet needs, exacerbated by the lack of empirical certainty in some existing treatments.

To address these challenges, we explored the feasibility of establishing a Global Clinical Trials Network for CP. We sought to leverage adaptive trial methodologies, known for their efficiency in accelerating treatment discovery, in fields such as oncology and respiratory disease.

Using the modified Delphi method, we purposively sampled CP experts from research active countries including panel representatives from each continent to gather consensus on the need for a network and to identify key governance, strategy, and operational aspects. This method allows for anonymous, iterative feedback from a diverse group of experts, facilitating consensus-building. Through two rounds of online surveys administered via Planorama, followed by a third round of discussions at a face-to-face summit to resolve differences, experts provided feedback on 73 statements derived from a literature review of recommendations. Prior to administration, statements were pilot-tested with 2 statisticians and 2 methodologists for rigour.

Participants rated their agreement to 73 statements on a 7-point numeric scale, from strongly disagree to strongly agree.

Descriptive statistics using medians and interquartile ranges (IQR) were used to analyse survey responses, with consensus defined as agreement among at least 80% of experts. Items with less than 60% agreement were discussed in-person to reach consensus. Written feedback on the whole group's median and IQR for each item was provided between rounds with a 2-week response time. Items that reached consensus were removed from subsequent rounds.

Of the 33 experts invited, 32 participated with a 100% retention rate across rounds. This diverse panel included individuals with lived experience, clinicians, and researchers from six continents. The Delphi resulted in unanimous agreement on the necessity of a global network co-led by individuals with CP. This network will aspire to improve the quality of life of people in all income contexts by addressing research priorities identified by the CP community and ultimately seek to include every person with CP in a protocol. Consensus was reached on governance, strategy, and operational matters, with Network funding requiring face-to-face discussion to reach resolution. It was agreed that grant funding should be sought to cover shared infrastructure costs (See [Supplementary file](#) for full results).

The commitment of the CP community to advancing research and improving outcomes is evident in this consensus. Establishing an international trials network for CP, made possible by the successfully awarded

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philanthropic grant funding from the Elsass Foundation and Cerebral Palsy Alliance, marks a significant step forward. By harnessing adaptive trial designs, this network endeavours to expedite the discovery and translation of effective CP treatments to answer people with CP's call.

Contributors

IN, MF, JBN, BD, MWS, MMN, and ARR conceived the study and its design. IN conducted the literature review. IN, ARR and MDJ had full access to the data, and take responsibility for the integrity of the data and accuracy of the analysis. All participants entered their own data via the online platform. All authors contributed to data analyses and to data interpretation. IN and AG wrote the main draft of the manuscript. All authors contributed to the final drafting of the manuscript, read and approved the final manuscript.

Data sharing statement

Participant data that underlie the results reported in this article, after de-identification may be made available upon request to researchers who provide a methodologically sound proposal. Proposals should be directed to Anina Ritterband-Rosenbaum arr@elsassfonden.dk to gain access, data requestors will need to sign a data access agreement.

Analyses will be limited to those approved with appropriate ethics and governance arrangements. All study documents which do not identify individuals (e.g. questionnaire and consent form) will be freely available on request.

Declaration of interests

IN, MF, BD, SC, PG, MM, MWS all received travel grants from the Elsass Foundation to support travel and accommodation to attend the round three face-to-face summit. IN also received competitive grant funds from the Elsass Foundation to establish the Network infrastructure.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.lanepe.2024.101015>.

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