

# Setting a Patient-Centered Research Agenda for Cerebral Palsy: A Participatory Action Research Initiative

Gross et al. (2018)  
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## For which topic were research priorities identified?

cerebral palsy

## In which location was the research priority setting conducted?

North America - USA

## Why was it conducted at all?

Cerebral palsy (CP) is an umbrella term for non-progressive, permanent brain disorders that affect development of movement and posture and precipitate a host of secondary and chronic comorbidities. A recent article reports that public funding of CP research between 2001 and 2013 increased, but that funding for studies of clinical interventions comprised only 19 percent of the funding and CP in adulthood comprised only 4 percent. A survey of an online community of parents and caregivers (n=1214) of children with CP conducted by the nonprofit organization CP NOW found that available medical information was judged by survey respondents (parents) to be inadequate to guide medical decision-making for children with CP.<sup>3</sup> Perceived inadequacy of available information reported by survey respondents may be attributable to the diversity of clinical presentations in this population, the broad array of treatments and medical providers involved in care of persons with CP, the lack of comparative effectiveness research for treatments, and the long-term, progressive nature of CP sequelae. Regardless of cause, perceived inadequacy of information points to the need for a research agenda involving the extended community of people living with CP and those providing healthcare to people with CP that informs medical decision-making for persons with CP.

## What was the objective?

to establish a patient-centered research agenda for cerebral palsy

## What was the outcome?

a ranking list of 16 research topics

## How long did the research prioritization take?

No information provided.

## Which methods were used to identify research priorities?

survey; webinar; workshop

## How were the priorities for research identified exactly?

Step 1: webinar series: five webinars: on Research CP initiative, methods for clinical comparative effectiveness research, quality improvement, patient-centered research and outcomes, and clinical and patient reported outcome registries. Step 2: survey: participants were asked: What research questions are most important to you? If you could identify one area to improve in the care or treatment of people with CP, what would that be?, 392 ideas were generated in CoDigital followed by a paired comparison process to prioritize the ideas. Step 4: data processing: research leadership team eliminated redundancies and reduced the set of ideas to a manageable number, resulting in 20 unique ideas. Step 5: workshop: list of 20-highest ranking, unique ideas, before workshop all participants submitted a description of their challenges with CP and desired outcomes for the workshop, during workshop: four small groups discussed ideas, plenary session: final discussion and consolidation produced final list of highest research priorities

## Which stakeholders took part?

Consumers (caregivers and persons with CP), professionals (clinicians and researchers), and advocates. Webinar: 275 participants. Survey: 201 participants. Workshop: 41 participants.

## How were stakeholders recruited?

For the webinar series, participants (n=275) were recruited from advocacy organizations, from the American Academy for Cerebral Palsy and Developmental Medicine, from Facebook groups, via advertising, and from followers of the CPRN and CP NOW websites. Workshop: Eighty-three applications were received for the in-person workshop in Chicago in June 2017. Invitations to the workshop were extended to 43 people including three personal care assistants; 41 could attend.

## Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the