

Stakeholder Perspectives on Re-engaging with Cerebral Palsy Research Studies Following Onset of COVID-19 in the United States

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Aim: To investigate the effect of the COVID-19 pandemic on perspectives towards participation in cerebral palsy (CP) research.

Method: A total of 233 individuals with CP or with a child with CP completed an online survey about participation in research during COVID-19. Readiness to participate in studies offering direct or no direct benefits to participants were analyzed in the context of the earliest timepoint of return to participation.

Results: Participants were consistently willing to participate sooner in studies that offered direct benefit than in those that did not. Adults responding for themselves had sooner timepoints for studies without direct benefit compared to parents answering for a child ($p=0.030$). GMFCS level, but not age or CP type, impacted the timepoint for studies without direct benefit ($p=0.017$). Personal values influenced selected timepoint for studies without direct benefit ($p=0.007$), while environmental factors impacted the timepoint for studies with direct benefit ($p=0.002$). Local COVID-19 incidence rates were not associated with timepoints for either research type, however respondents expected precautions to be taken if they chose to participate.

Interpretation: As the pandemic evolves, researchers should consider the perspectives of potential participants as well as ethical and safety factors when re-initiating in-person CP research.