Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

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ORIGINAL RESEARCH

Stakeholder Perspectives on Engaging With Cerebral Palsy Research Studies After Onset of COVID-19 in the United States

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Abstract

Objective: To investigate the effect of the coronavirus disease 2019 (COVID-19) pandemic on perspectives toward participation in cerebral palsy (CP) research.

Design: An online survey with questions relating to the comfort levels of research participation was filled out by people who had CP or had a child with CP.

Setting: The online survey was administered through Research Electronic Data Capture platform.

Participants: A total of 233 (n=233) individuals with CP (42.5%; n=99) or with a child with CP (57.1%; n=133) consented and at least partially completed the online survey (n=210 complete; n=23 partially complete). All participants resided in the United States.

Interventions: Not applicable.

Main Outcome Measures: Readiness to participate was analyzed in the context of the time point for research participation during COVID-19 and whether or not the study offered direct benefits to participants.

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 time points for studies without direct benefit compared with parents answering for a child (P=.030). Gross Motor Function Classification System level, but not age or CP type, affected the time point for studies without direct benefit (P=.017). Personal values influenced selected time point for studies without direct benefit (P=.007), whereas environmental factors affected the time point for studies with direct benefit (P=.002). Local COVID-19 incidence rates were not associated with time points for either research type; however, respondents expected precautions to be taken if they chose to participate.

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

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Research studies are the primary mechanism by which clinicians and scientists improve understanding of pathophysiology and treatment options for cerebral palsy (CP), a group of movement disorders caused by injury or disruption to the developing brain.[1] An estimated 60%-80% of rehabilitation studies in the United States do not meet their expected sample size,[2] and studies that focus on pediatric populations, including CP, are prone to difficulties in recruiting the number of participants required for scientific validity.[3,4]

The coronavirus disease 2019 (COVID-19) global pandemic has resulted in widespread stay-at-home orders and social distancing, which has affected the ability to carry out in-person research studies. Some regions began to reopen businesses and schools by summer of 2020, but there is not consensus on how to ethically

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and safely reinitiate human research. Scientists must consider visit-related factors, policy-related factors, research facility preparedness, and research participant perspectives[5] in evaluating the overall risk of resuming human research. The current study investigates the personal and environmental factors that influence comfort levels of participant stakeholders for participating in CP research during the COVID-19 pandemic.

Methods

An online survey was developed by the study team with review by 6 stakeholders who had CP or a child with CP. The survey was available online between May 6 and July 7, 2020 and disseminated through the Research Electronic Data Capture[6,7] platform. Informed consent was collected from all participants. The survey consisted of up to 60 questions, with 14 specifically related to comfort with in-person research study participation during the COVID-19 pandemic (supplemental fig S1, available online only at http://www.archives-pmr.org/). This study was approved by Northwestern University's Institutional Review Board.

Recruitment

Participants had to reside in the United States and be either (1) a parent or legal guardian of a minor with CP or (2) an adult with CP. Participants were recruited directly via email if they had previously participated in pediatric studies at Northwestern University or consented to be contacted through the web-based recruitment tool ResearchMatch.org.[8] Eligible members of the Cerebral Palsy Research Registry[9] were sent a recruitment notification, and clinical partners were encouraged to share the study with eligible patients. Finally, social media sites (Facebook, Twitter, Instagram) were used to share the survey link.

Data analysis

All statistical analyses were conducted using SPSS software[a] with $P<.05$ considered statistically significant. Descriptive analysis was completed for age, sex, ethnicity, race, CP diagnosis, and Gross Motor Function Classification System (GMFCS) level. Survey data were analyzed to address the following research questions:

Q1: How soon are potential participants willing to participate in research?

Participants were asked to identify the earliest milestone at which they would be comfortable joining a research study. They were asked to separately answer for studies with potential for direct benefit (ie, clinical trials of interventional physical and occupational therapy studies, drug and treatment efficacy, intensive training) and with no direct benefit (ie, studies aiming to understand basic scientific and biomechanical background of CP). The milestones presented to respondents included: (1) now; (2) after lifting of local stay-at-home orders; (3) after widespread testing for COVID-19; (4) after availability of COVID-19 vaccination; and (5) not in the foreseeable future. Because milestones are ordered chronologically, time point for research participation was coded for analysis with earliest selected time point for a given activity, with the assumption that the respondent would also be willing to participate for the later time points. Analysis focused on time points for studies that have potential direct benefit and studies that have no direct benefit.

Q2: How does participating in research activities compare with other activities?

Participants were asked the earliest milestone (as in Q1) they would engage in the following activities: (1) personal care appointments; (2) social or recreational activities; (3) routine medical appointments; and (4) medical appointments for a new concern. Chi-square tests were performed to analyze whether there was association between the time point for research participation for studies that have potential direct benefit, the time point for research participation for studies that have no direct benefit, and the time points they were comfortable participating in nonresearch activities. Spearman correlations were observed to determine the strengths of association.

Q3: Are demographic characteristics of the potential participant associated with time point for research participation?

We performed separate Kruskal-Wallis tests with time point for research participation for studies that have potential direct benefit and time point for research participation for studies that have no direct benefit as dependent variables and age, GMFCS level, or CP diagnosis as independent variables. For significant main effects, pairwise comparisons were performed with Bonferroni correction for multiple tests.

Q4: Which personal values are associated with time point for research participation?

Personal values included self-rated value placed on CP research overall and participation in CP research. Linear regression was performed with each of these values as predictors and with time point for research participation for studies that have potential direct benefit and time point for research participation for studies that have no direct benefit as the outputs.

Q5: How are environmental factors, including the overall COVID-19 risk, associated with choices about engaging in research activities?

The risk of COVID-19 was represented by the incidence rate (cases per 100,000 persons) for each respondent's state on the date of survey completion, which was obtained from the COVID-19 Data Repository by the Center for Systems Science and Engineering at Johns Hopkins University.[10] This COVID-19 risk metric, along with preferred location of research participation (regardless of COVID-19 consideration) and transportation typically used for medical appointments, was used in linear regression models to determine whether environmental factors could predict when individuals were willing to participate in in-person research studies (time point for research participation for studies that have potential direct benefit and time point for research participation for studies that have no direct benefit).

List of abbreviations:

COVID-19	**coronavirus disease 2019**
CP	**cerebral palsy**
GMFCS	**Gross Motor Function Classification System**

Q6: What are common responses about participant decision making during COVID-19?

Open-ended questions about the effect of COVID-19 on research participation decisions were categorized first by whether it had an effect (yes, no, unsure) and further organized by stated reason(s) for response.

Results

Participants

In total, 241 individuals consented and 233 submitted complete (n=210) or partially complete (n=23) surveys. The final sample represents a 10.3% response rate of those directly contacted via e-mail, ResearchMatch.org, and the Cerebral Palsy Research Registry (n=2266). Study sample characteristics are shown in table 1.[11-14] Compared with the United States 2010 Census data, the sample is broadly representative of the national population in terms of sex, ethnicity, and racial composition. Notably, the sample included more respondents who were parents of children with CP (57.1%; n=133) than adults with CP (42.5%; n=99), as opposed to the national population, which consists of 24% minors and 76% adults.[15] When results are similar among the caregivers of a child and adults with CP, the term respondent is used to generalize to both; when the results or trends are different, caregiver and adult responses are reported independently.

Participants came from 33 states, as illustrated in supplemental fig S2 (available online only at http://www.archives-pmr.org/). Over half the respondents reside in Illinois (54.5%; n=127). The next 3 most represented states were Indiana (4.72%; n=11), California (3.86%; n=9), and New York (3.43%; n=8). The incidence rates of COVID-19 across the country for the dates of the survey are represented in maps shown in supplemental fig S2 (available online only at http://www.archives-pmr.org/). The total incidence rate in the United States increased from 18,110 to 41,637 cases per 100,000 persons over the duration of the survey.

Table 1 Characteristics of study sample

Characteristics	Survey Sample		Population (%)[11-14]
	n	%	
Total no. of respondents	233	100	
Age group (y)[11]			
0-1	2	0.9	
2-3	10	4.3	
4-5	14	6.0	
6-11	53	22.7	
12-17	54	23.2	
Total: <18	133	57.1	24.0
18-30	45	19.3	
31-50	36	15.5	
51+	18	7.7	
Total: >18	99	42.5	76.0
Unknown/not reported	1	0.4	
Sex assigned at birth[11]			
Female	120	51.5	50.8
Male	112	48.1	49.2
Unknown/not reported	1	0.4	
Ethnicity[12]			
Hispanic or Latino	23	9.9	16.3
Not Hispanic or Latino	204	87.6	83.7
Unknown/not reported	6	2.6	
Race[12]			
American Indian or Alaska Native	2	0.9	0.9
Asian	9	3.9	4.8
Black or African American	24	10.3	12.6
Native Hawaiian or Other Pacific Islander	1	0.4	0.2
White	175	75.1	72.4
≥2 Races	6	2.6	2.9
Unknown/not reported	16	6.8	
GMFCS[13]			
Level I	60	25.8	34.2
Level II	65	27.9	25.6
Level III	33	14.2	11.5
Level IV	37	15.9	13.7
Level V	35	15.0	15.6
Unknown/not reported	3	1.3	
CP diagnosis[14]			
Hemiplegia	72	30.9	22.6
Diplegia	60	25.8	22.4
Quadriplegia	76	32.6	25.0
Other	19	8.2	30
Unknown/not reported	6	2.6	

NOTE. Survey percentages are compared with national census and previously published reports on distribution of CP. National census and CP population percentages from references.[11-14]

Time points for research participation (Q1)

As shown in figure 1, more respondents indicated willingness to participate in direct benefit studies compared with no direct benefit at each of the time points. Over a fifth (23.1%; n=49) of the respondents indicated time point for research participation at survey completion ("now") in a no direct benefit study, whereas 39.4% (n=84) would participate "now" in a direct benefit study. For both study types, the percentage of respondents willing to participate has the steepest rise between "now" and the "lifting of local stay-at-home orders." A direct benefit study has the smallest change between "widespread testing" and "availability of a vaccination" (11.2%; n=24), whereas a no direct benefit study has the smallest change between "lifting of stay-at-home orders" and "widespread testing" (20.3%; n=43). Frequencies of responses for each time point for research participation can be found in supplemental table S3 (available online only at http://www.archives-pmr.org/).

Perceptions of research studies compared with other appointments (Q2)

As shown in figure 1, at the time of survey completion, the majority of respondents were comfortable going to a medical appointment for a new concern (61%; n=130), but few were willing to participate in a social or recreational activity (9%; n=19). Significant associations were found for all combinations tested ($P<.001$). Research studies with direct benefit were most closely associated with a routine medical appointment ($\rho=0.564$, $P<.001$), whereas no direct benefit studies had the highest correlation with a social or recreational activity ($\rho=0.600$, $P<.001$). Both types of research studies were least correlated with a medical appointment for a new concern (direct

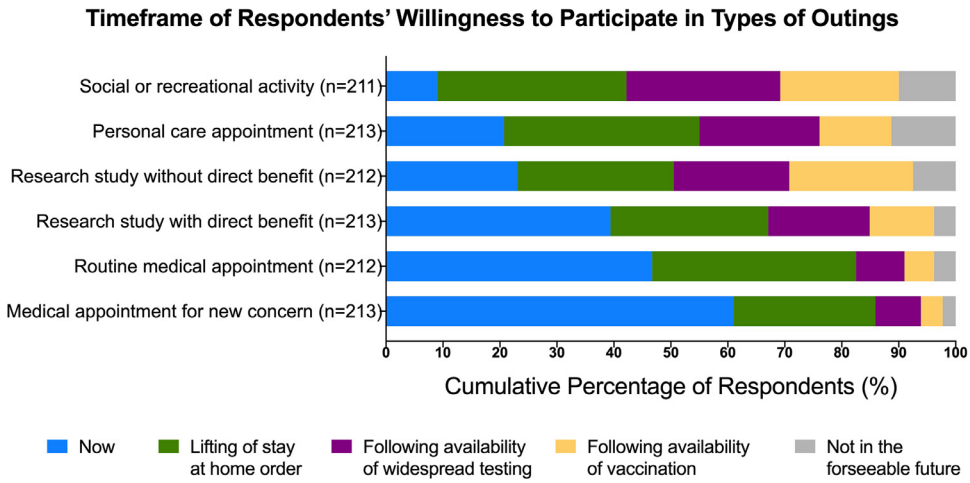

Fig 1 Number of respondents willing to partake or have their child partake in each of 6 types of outings—social or recreational activity, personal care appointment, research study without direct benefit, research study with direct benefit, routine medical appointment, or a medical appointment for a new concern—at each of the COVID-19 related milestones. The cumulative percentage of respondents is shown, such that the number of respondents that was ready at each time point was added with the number of respondents that stated they were ready to participate at earlier time points.

Table 2 Ranking of associations between direct benefit and indirect benefit research studies with the other types of outings

Research Study With Direct Benefit			Research Study Without Direct Benefit		
	Spearman (*n*)	χ^2 (*df*)		Spearman (*n*)	χ^2 (*df*)
Routine medical appointment	0.564 (*210*)	213.287 (*16*)	Social or recreational activity	0.600 (*210*)	204.413 (*16*)
Personal care appointment	0.554 (*212*)	165.307 (*16*)	Personal care appointment	0.543 (*212*)	181.356 (*16*)
Social or recreational activity	0.522 (*210*)	160.841 (*16*)	Routine medical appointment	0.476 (*210*)	140.239 (*16*)
Medical appointment for new concern	0.484 (*211*)	246.939 (*16*)	Medical appointment for new concern	0.384 (*210*)	91.778 (*16*)

NOTE. Associations were ranked by Spearman correlation values, with a higher Spearman value indicating a stronger association and a lower Spearman value indicating a weaker association. For each correlation, Spearman values are reported with the number of valid samples (*n*), and χ^2 values are reported with degrees of freedom (*df*). The *P* values for Spearman and χ^2 tests for all correlations were found to be <.001.

benefit: ρ=0.484, *P*<.001; no direct benefit: ρ=0.384, *P*<.001) (table 2).

Time point for research participation relationship to demographics (Q3)

Whether the survey respondent was answering for themselves (as an adult with CP) or for their child did not affect the time point for research participation for studies that have potential direct benefit (*H*[1]=0.008, *P*=.930) but did significantly affect the time point for research participation for studies that have no direct benefit (*H*[1]=4.708, *P*=.030), where adults with CP had an earlier time point for research participation for studies that have no direct benefit than parent respondents (fig 2A). At time of survey completion, more adults (31.9%; n=30) than parents (16.2%; n=19) responded "now," representing the greatest difference between groups. Group differences reduced chronologically, with almost the same percentages willing to participate "after the availability of vaccination" (adults: 92.6%, n=87; parents: 92.3%, n=108) for no direct benefit studies.

Across all age groups, time point for research participation was on average sooner for direct benefit than no direct benefit (see fig 2B). Adults with CP in the 31- to 50-year age group reported the earliest time point for research participation; caregivers of children 2-3 years old reported the earliest time point for research participation. No significant differences were found between the age groups in time point for research participation for studies that have potential direct benefit (*H*[6]=6.360, *P*=.384) nor time point for research participation for studies that have no direct benefit (*H*[6]=9.856, *P*=.131).

For both types of studies, individuals and caregivers of children in GMFCS Level IV and Level V were the least willing to participate at earlier time points (see fig 2C). On average, individuals or caregivers of children in GMFCS Level III were the most willing to participate across all time points for research participation milestones. Although there were no significant differences between GMFCS levels in time point for research participation for studies that have potential direct benefit (*H*[4]=3.917, *P*=.417), there were significant differences with time point for research participation for studies that have no direct benefit (*H*[4]=12.008, *P*=.017). Specifically, there were significant differences in the time point for research participation for studies that have no direct benefit between Level III and Level IV (*t*=−45.172, *P*=.024) and between Level III and Level V (*t*=−45.486, *P*=.035). To account for the uneven sample sizes across the GMFCS levels and confirm the significant differences identified by the initial analysis, a post hoc Monte Carlo simulation was run with 100 iterations, with 30 participants with Level I and Level II randomly chosen for inclusion in analysis with Levels III, IV, and V. Across the 100 iterations, there was no significant relationship between GMFCS level and time point for research participation for studies that have potential

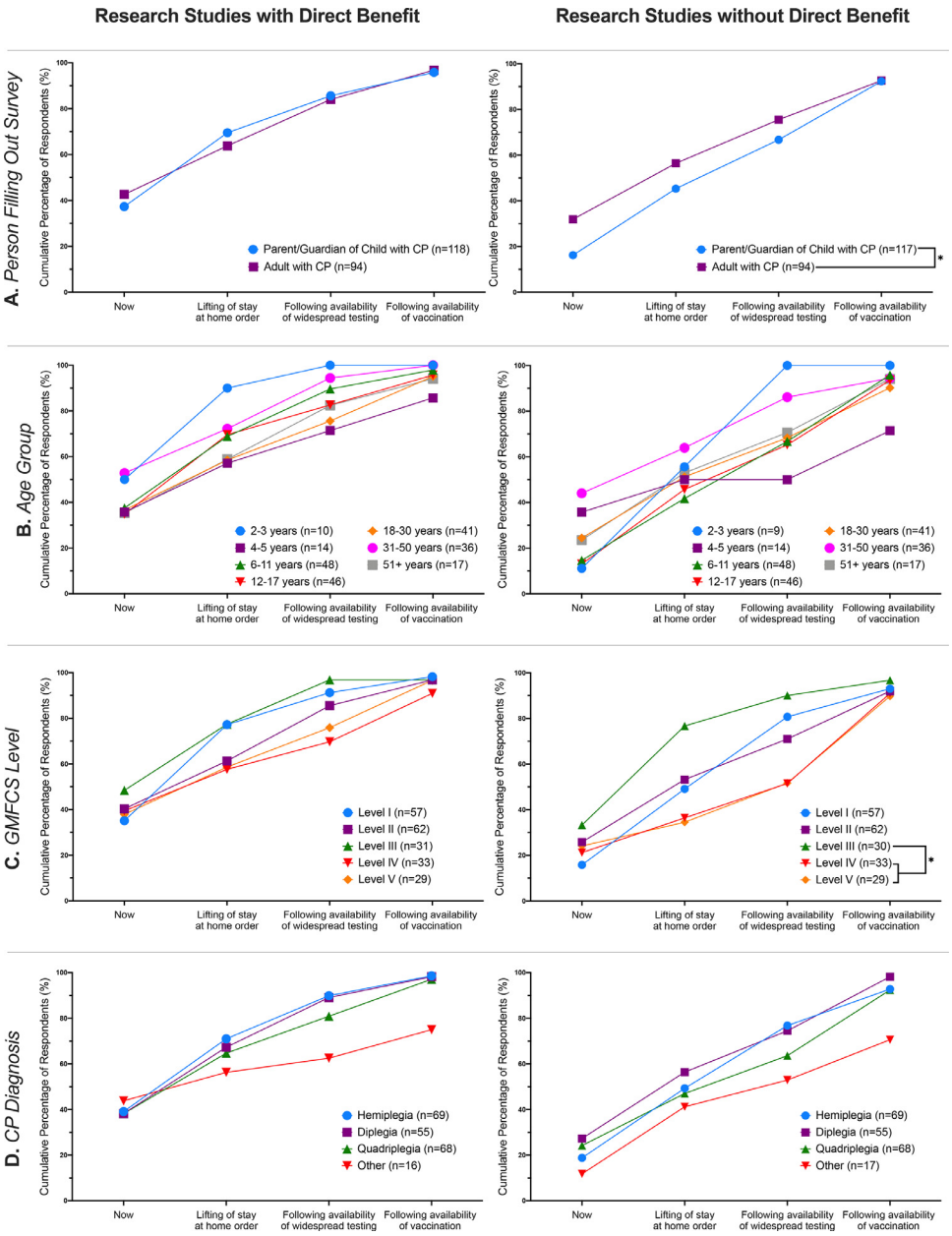

Fig 2 Cumulative number of respondents willing to participate in research studies that offer direct benefit (left) and studies that do not offer direct benefit (right), separated by **(A)** minor or adult status of respondent, **(B)** age group, **(C)** GMFCS level, and **(D)** type of CP diagnosis. *Significance at $P<.05$.

direct benefit, but there remained a significant relationship between GMFCS level and time point for research participation for studies that have no direct benefit. Furthermore, of the iterations showing significant groupwise differences in time point for research participation for studies that have no direct benefit, 4% showed differences between Level II and Level III (average t=16.625, average P=.0335), 100% showed differences between Level III and Level IV (average t=−29.0386, average P=.0259), and 96% showed differences between Level III and Level V (average t=−28.8884, average P=.0355).

No significant differences were found between the CP types in time point for research participation for studies that have potential direct benefit (H[3]=1.186, P=.756) nor time point for research participation for studies that have no direct benefit (H[3]=4.579, P=.205). On average, there are more adults or caregivers of children with hemiplegia and diplegia willing to participate at sooner time points than those with quadriplegia, whereas the respondents who reported "Other" for CP diagnosis were the least willing to participate (see fig 2D).

Personal predictors of time point for research participation (Q4)

The mean for self-rated value placed on CP research (of 100) was 94.3±9.05, and value placed on their own participation in CP research was 88.6±16.6. The regression model for time point for research participation for studies that have no direct benefit was significant (table 3) where both value of research and value of participation in research were significant predictors. The time point for research participation for studies that have no direct benefit

was later as value placed on research increased (P=.037) and sooner as value placed on participation increased (P=.002). The model for time point for research participation for studies that have potential direct benefit was not significant (see table 3).

Environmental predictors of time point for research participation (Q5)

Prior to COVID-19, 69.5% (n=162) of respondents would have participated in research in a research laboratory, and 43.3% (n=101) of respondents would have participated in a school. These 2 locations were significant predictors (research laboratory: P=.001; school: P=.022) for a sooner time point in the time point for research participation for studies that have potential direct benefit regression model with research location (see table 3). The regression model for time point for research participation for studies that have no direct benefit was not significant (see table 3).

Qualitative responses to the effect of COVID-19 on research participation (Q6)

A total of 72% of survey participants (n=169) answered whether COVID-19 affected their feelings on research participation. Participant responses reflected a range in whether COVID-19 affected feelings on research participation, and many provided additional reasons for their perceptions (fig 3). The most common reasons included if proper precautions were taken, travel distance to and location of the study site, or if the participant or a family member was immunocompromised. Selected quotes can be found in supplemental table S4 (available online only at http://www.archives-pmr.org/).

Discussion

This study explored the comfort level of participating in research by individuals with CP during the COVID-19 pandemic by analyzing willingness to participate in 2 key categories of in-person research studies: studies that offer potential direct benefit and studies that do not offer direct benefit. The findings revealed a number of important considerations for researchers as they plan research during COVID-19.

The majority of respondents were willing to attend either an acute or routine medical appointment in the near future, but few were comfortable with casual, nonessential outings, such as personal care or social activities, potentially because of immunocompromised family members or anxiety about the pandemic.

Table 3 Linear regression parameters of the effect of personal predictors and environmental predictors on the readiness to return to research studies with and without direct benefit

	Personal Predictors			
	Research Study With Direct Benefit $F_{2,201}$=0.269, P=.764		Research Study Without Direct Benefit $F_{2,200}$=5.117, P=.007*	
	β	P Value	β	P Value
Value placed on				
Research	0.049	.558	0.172	.037*
Participation	−0.057	.493	−0.259	.002*
	Environmental Predictors			
	Research Study With Direct Benefit $F_{13,191}$=2.692, P=.002*		Research Study Without Direct Benefit $F_{13,190}$=1.453, P=.139	
	β	P Value	β	P Value
COVID-19 incidence	−0.049	.486	−0.077	.296
Location				
Clinic/hospital, already receiving services	0.048	.488	0.033	.643
Clinic/hospital, not already receiving services	−0.111	.137	−0.127	0.104
Park/community center	0.017	.829	0.031	.698
Research laboratory	−0.267	.001*	−0.159	.046*
School	−0.178	.022*	−0.128	.112
Home	0.015	.832	−0.031	.668
Other location	−0.050	.463	−0.003	.961
Transportation				
Drive self	0.137	.161	0.175	.087
Family member drives	0.070	.401	0.096	.272
Public transportation	0.076	.384	0.036	.694
Car service	1.045	.297	0.091	.287
Other transportation	0.057	.452	0.053	.502

NOTE. Whole model output and significance values are reported, as are coefficients and significance of individual predictors; β values refer to the standardized coefficients resulting from the regression.
* Significance at P<.05.

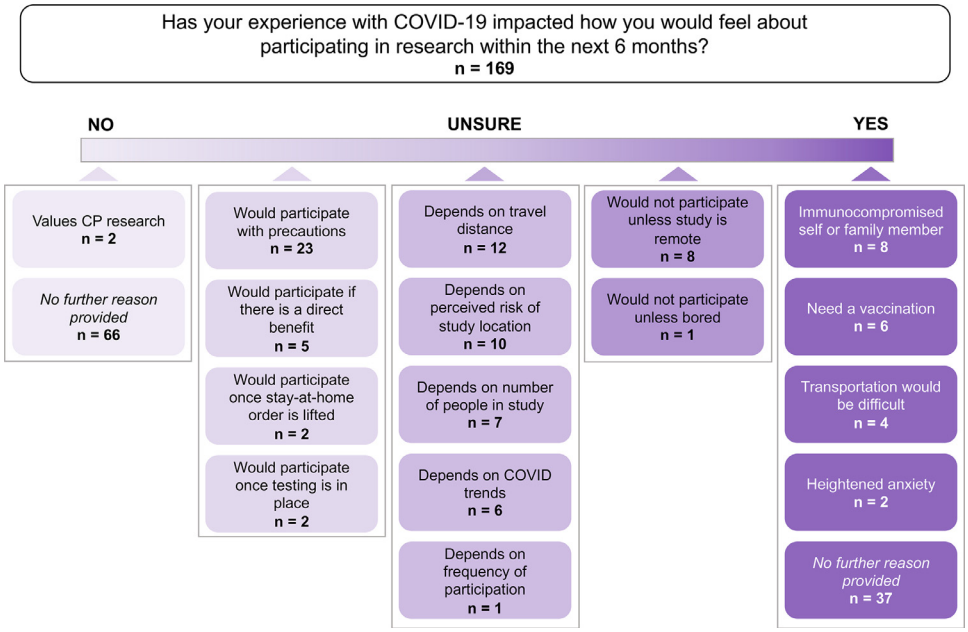

Fig 3 Spectrum showing the range of qualitative responses to the effect (or lack thereof) that COVID-19 had on participants' feelings towards research participation (n=169, 72.5% of total survey respondents). Using keywords, responses were first categorized broadly into "yes, research participation was affected," "no, research participation was not affected," and "unsure if research participation was affected." Then, the "yes" and "no" responses were subcategorized into "strong yes," "strong no," "leaning yes," and "leaning no." The "leaning yes" and "leaning no" categories indicated that the respondent's feelings could be swayed by additional factors, which are listed. Some of the "strong yes" and "strong no" responses provided reasoning, which are also shown. Many responses fell into multiple categories. The ends of the spectrum represent "strong yes" and "strong no" responses, whereas the center of the spectrum represents "unsure responses." The proximity of responses to either end of the spectrum represents the strength of the "yes" or "no" response.

Research participation is perceived as less urgent than medical needs but as more important than casual outings, with direct benefit studies similar to a routine medical visit and no direct benefit studies similar to a social activity. Although specific dates for these milestones depend on local regulations and will vary by location, these results illustrate a general timeline that can be followed by researchers when preparing for engagement in research.

Although COVID-19 is rapidly evolving, it has been shown that older adults with the illness have higher mortality rates (median age of death >65 years),[15] and individuals of any age with underlying medical conditions are more susceptible to the disease and have worse prognosis.[16] Despite elevated risk, age was not a significant factor in time point for research participation, although a related factor of the person completing the survey (adult with CP or parent/guardian of a minor with CP) was significant. Compared with adults answering for themselves, parents were less comfortable with their children participating. This may be related to the total number of individuals from a family that need to be engaged, a parental drive to be protective, or a fear of their own child being a "guinea pig" for clinical testing.[17]

GMFCS level did have a significant effect on the willingness to participate in a no direct benefit study, and Level IV or Level V groups who are more likely to have severe comorbidities[18,19] were the most conservative in their approach. In contrast, GMFCS level did not have an effect on time point for research participation for studies that have potential direct benefit, and the type of CP diagnosis did not affect time point for research participation in either type of study. Post hoc Monte-Carlo tests revealed that results were robust to sample size differences.

The more respondents valued their own participation in research, the sooner they were likely to be willing to participate in no direct benefit studies. Conversely, value of research in general (disregarding their own involvement) actually predicted a later time point for research participation. Although these relationships were significant, the notable finding is that although research and participation are highly valued by respondents, risk of COVID-19 exposure may affect personal decision on when to participate.

Environmental factors related to pre-COVID-19 life appeared to have a small influence on an individual's time point for research participation for studies that have potential direct benefit but not time point for research participation for studies that have no direct benefit. Particularly, selection of a research laboratory or school as a potential study location indicated that respondents would participate sooner in studies that offer direct benefit. This could be related to perceived structure of these 2 locations instilling confidence in the quality of research and may extend to an expectation of precautions and safety measures against COVID-19,[20,21] although this would require further investigation. Although few respondents (32.6%; n=76) considered outdoor recreational spaces for research participation prior to COVID-19, outside may be a reasonable solution in some study locations during the pandemic[22] for safe in-person participation.

Surprisingly, the local burden of COVID-19, represented by the local COVID-19 incidence rate on the day the respondent took the survey, did not have a significant effect on the time point for research participation for either type of research study. We did not specifically gauge respondents' knowledge of their community's burden at the time of the survey. Recent surveys revealed variable understanding of the mode of transmission and symptoms of COVID-19,[23-25] with considerable inaccurate beliefs regarding origination, transmission, and prevention of COVID-19,[24] including among those with chronic conditions.[25] Although

misunderstanding of COVID-19 information could skew reactions, there are also local burdens not directly captured by incident rate or other quantitative values that may influence responses and may be reflected in open-ended answers.

Study limitations

We used the COVID-19 incidence rates recorded at the state level; however, finer precision at the county or zip code level may yield a tighter coupling with local attitudes, especially in metropolitan areas. Additionally, the majority of participants resided in Illinois and only 33 states were represented, introducing a potential geographic bias in the results. Demographically, there is a slight underrepresentation of minorities (Hispanic/Latino ethnicities and non-White races) and no data indicating socioeconomic status of respondents, both of which are factors that are significantly correlated with COVID-19 burden.[26] Finally, respondents were asked to answer some questions as they would have prior to COVID-19, which may have been affected by recall bias.

Conclusions

There is limited guidance on how human research, particularly in pediatric and at-risk populations, should be safely carried out during COVID-19. The current study provides insight into the perceptions of individuals with CP or their caregiver when considering engaging with research. Results from this study could also serve as the basis for further exploration about how readiness for participation may be improved in collaboration with potential participants for a specific study. The relatively large numbers of respondents willing to engage in research during the COVID-19 pandemic demonstrate the importance of partnership for new discovery in CP. It is therefore the responsibility of investigators to reach out to potential participants or participant representatives to implement research in a way that is both respectful of necessary scientific rigor and responsible to the public health crisis.

Supplier

a SPSS software version 26; SPSS Inc.

Keywords

Cerebral palsy; COVID-19; Pandemics; Rehabilitation

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