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UK research priority setting for childhood neurological conditions

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Abstract

Aim: To identify research priorities regarding the effectiveness of interventions for children and young people (CYP) with childhood neurological conditions (CNCs). These include common conditions such as epilepsies and cerebral palsy, as well as many rare conditions.

Method: The National Institute for Health and Care Research (NIHR) and the James Lind Alliance (JLA) champion and facilitate priority setting partnerships (PSPs) between patients, caregivers, and clinicians (stakeholders) to identify the most important unanswered questions for research (uncertainties). A NIHR–JLA and British Paediatric Neurology Association collaboration used the JLA PSP methodology. This consisted of two surveys to stakeholders: survey 1 (to identify uncertainties) and survey 2 (a prioritization survey). The final top 10 priorities were agreed by consensus in a stakeholder workshop.

Results: One hundred and thirty-two charities and partner organizations were invited to participate. In survey 1, 701 participants (70% non-clinicians, including CYP and parent and caregivers) submitted 1800 uncertainties from which 44 uncertainties were identified for prioritization in survey 2; from these, 1451 participants (83% non-clinicians) selected their top 10 priorities. An unweighted amalgamated score across participant roles was used to select 26. In the final workshop, 14 health care professionals, 11 parent and caregivers, and two CYP ranked the 26 questions to finalize the top 10 priorities. Ten top priority questions were identified regarding interventions to treat CYP with CNCs and their associated comorbidities, for example, sleep, emotional well-being, and distressing symptoms.

Interpretation: The results of this study will inform research into the effectiveness of interventions for children with neurological conditions.

Abbreviations: BPNA, British Paediatric Neurology Association; CNC, childhood neurological condition; CYP, children and young people; JLA, James Lind Alliance; NIHR, National Institute for Health and Care Research; PSP, priority setting partnership.

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For affiliations refer to page 8.

Childhood neurological conditions (CNCs) are a wide and heterogeneous group of conditions affecting a child's central and peripheral nervous systems and include many rare and more common diseases. They are associated with significant medical comorbidities with many children developing life-altering disability.

Approximately 600 000 people in the UK have epilepsy, with young people under 18 years accounting for around 10% of this total.[1] Routinely collected health data in England and Wales estimate that there were 22 000 children and young people (CYP) aged 0 to 25 years with cerebral palsy (CP) in 2020 and at least 70 000 children and adults living in England with 1 of over 60 muscle-wasting conditions.[2,3] Based on the epidemiological information regarding these three most common CNCs, the estimated prevalence may be in excess of 9:1000 (the population of England and Wales aged 0–24 years in 2021 was 17 349 485).[4]

Although there is greater understanding of the aetiology and pathophysiology of CNCs, further research into the evidence for interventions is required; furthermore, prioritization is crucial considering the limited funding.[5]

The National Institute for Health and Social Care Research (NIHR) funds the infrastructure of the James Lind Alliance (JLA) to oversee priority setting partnerships (PSPs). PSPs aim to help patients, carers, and clinicians to work together to agree which are the most important evidence uncertainties affecting their particular interest to influence the prioritization of future research in that area.[6] More than 150 PSPs across many conditions have now been completed, with emerging evidence of their impact.[7,8]

By setting research priorities, this PSP aimed to improve the health and well-being of CYP (aged 0–25 years) with neurological conditions, about which there is uncertainty as to the effectiveness of medical and non-medical treatments, therapies, and medical and surgical procedures (interventions). The PSP was a collaboration between the NIHR–JLA and the British Paediatric Neurology Association (BPNA).

What this paper adds

- Priorities for childhood neurological conditions included interventions for neonatal seizures, sleep, mental health, and communication.
- These research priorities should inform future research and policy.

METHOD

We adopted the NIHR–JLA PSP methodology,[9] which has been developed and used to guide previously completed PSPs. The process is outlined in this article and is also detailed in Appendix S1.

The core steps were: (1) convening a steering group and expert advisers consisting of patients, parents, and clinician representatives to cover the wide spectrum of disorders. Clinicians were selected by the PSP chairs to represent the breadth of subspecialties in paediatric neurology and neurodisability. Five parent and carers and three young people were chosen from charitable organizations in contact with the BPNA executives and PSP chairs. The steering group agreed on the scope of the PSP to focus on intervention-based research priorities meaningful to all stakeholders (Appendix S1); (2) identifying stakeholders and participants who were made aware of the project and were invited to contribute. The PSP and the surveys were promoted through the BPNA, the National Royal Colleges and the British Academy of Childhood Disability, condition-specific charities, and national organizations. CYP and their parents were approached via clinical services, through newsletters, and via peer-to-peer support groups. Survey weblinks were circulated via e-mail to these stakeholders. Participants completed online surveys using SurveyMonkey. Consent was obtained at the start of each survey, before collection of demographic information. The workshop participants were purposively sampled from survey 2 participants (Appendix S1); (3) identifying treatment uncertainties gathered through survey 1 (Appendix S1) and from reviewing existing national and international research recommendations (performed by the information team). Conditions where there have been other recently published PSPs (e.g. autism spectrum disorders) were excluded. A UK epilepsy PSP was developed subsequently and reported in parallel;[10] (4) analysing uncertainties and generating research summary questions from survey 1. The Framework Method[11] was used in two stages to organize the submitted uncertainties, create structured research questions, and check evidence to ascertain that uncertainties were unanswered. The first stage was used to order uncertainties into themes and remove duplicate or out-of-scope uncertainties; the second stage was used to review and either eliminate further questions or refine those remaining into sets from which structured summary questions were drafted for the literature review. After the literature searches were completed, the results were presented to the steering group. Members discussed and refined the summary questions from the original uncertainties and reduced them to a 'long list' for survey 2, the prioritization survey (Appendix S1); (5) prioritizing structured research questions through survey 2: participants selected their priorities. The sum of the rankings of the questions for each participant group gave a final priority order (Appendix S1 and Table S1); and (6) a priority workshop was held with representation from all stakeholder groups to agree the top 10 priorities through consensus discussion (Appendix S1).

Ethics approval

This study did not require ethical approval (based on the Health Research Authority Decision-Making Tool; https://

www.hra-decisiontools.org.uk/research/about.html). However, all participants provided informed consent at the start of the survey before taking part (Appendix S1).

RESULTS

The research priorities were disseminated by the BPNA in November 2022, just over 3 years from the establishment of the steering group and expert advisers, setting the scope in October 2019. One hundred and thirty-two charities and partner organizations were invited to participate (Appendix S2). The overview and timeline of the data collection and analysis of this PSP is illustrated in Figure 1.

Survey 1: identifying uncertainties

For survey 1 (open September 2020–January 2021), 701 participants (Table 1), submitted a total of 1800 uncertainties, from which 297 within the scope were discussed, grouped, and converted to summary questions in the second analysis, and went through evidence checking (Appendix S1). The remaining 61 draft questions were then refined by the steering group to produce 44 summary questions that went forward to form survey 2 (Table 2).

Survey 2: prioritization

By January 2022, 1624 people had accessed the survey (their demographics are shown in Table 1), and 1451 participants submitted up to 10 priorities. The rankings according to stakeholder groups and the sum were taken forward to rank the 44 questions. These were taken to the steering group for consensus on the top 26 questions for the workshop (Table S1).

Final workshop

Twenty-seven participants attended: 14 health care professionals, 11 parents and carers, and two young people. Three of the participants attended virtually. Facilitation of the sessions led to discussion from all stakeholder groups to rank all 26 questions and produce the final top 10 priorities (Table S2 and Table 3).

The top 10 research priorities

Priority 1: Can early therapy interventions improve functional and developmental outcomes in infants experiencing brain injury during pregnancy or infancy?

Twelve original uncertainties were combined to create this summary question. Despite increasing knowledge regarding postnatal cortical network and neural reorganization after neonatal brain injury, and increasing evidence that interventions taking advantage of neonatal neural plasticity may influence long-term neurodisability, and comorbidities, consensus is still lacking about how best to deliver these interventions and outcomes, which have been highly variable across different patient groups.[12]

Priority 2: What are the most effective interventions to support sleep in children and young people with neurological conditions?

There were five original uncertainties regarding the pharmaceutical and non-pharmaceutical management of sleep. Apart from melatonin,[13] there are no randomized controlled trials showing that medication improves insomnia and sleep fragmentation; yet, multiple medications, including clonidine, are often used for this purpose. Systematic reviews of melatonin are focused on different populations, including children without neurological conditions; these show low certainty of evidence, with modest reduction in sleep latency and increase in sleep duration.[14,15] Furthermore, there is lack of consensus in how to best assess the efficacy of sleep interventions.[16] Children with primary 'neurological' sleep disorders are often therapeutic orphans. For example, there are no licensed drugs for children in the UK with restless leg syndrome or narcolepsy (sodium oxybate is used only under clinical commissioning criteria). Comprehensive clinical guidelines were published in 2021, but were based on limited evidence in children.[17]

FIGURE 1 Outline of the British Paediatric Neurology Association–James Lind Alliance priority setting partnership: process and timeline.

TABLE 1 Demographics of the participants in surveys 1 ($n = 701$) and 2 ($n = 1451$).

	Survey 1, *n* (%)	Survey 2, *n* (%)
Participant role*	($n = 728$)	($n = 1644$)
Person affected by a neurological condition < 26 years	62 (8.5)	148 (9.0)
Parent or caregiver of a person affected by a neurological condition before the age of 26 years	382 (52.5)	791 (48.1)
Other family member or friend of a person affected by a neurological condition before the age of 26 years	31 (4.3)	299 (18.2)
Health professional: doctor	142 (19.5)	133 (8.1)
Allied health professional	53 (7.3)	117 (7.1)
Health professional: nurse	26 (3.6)	36 (2.2)
Professional working for another organization (e.g. charity)	13 (1.8)	28 (1.7)
Social care professional	1 (0.1)	9 (0.5)
Education professional	16 (2.2)	50 (3.0)
Preferred not to say	2 (0.3)	33 (2.0)
Age (years)	($n = 701$)	($n = 1451$)
< 6	7 (1.0)	11 (0.8)
6–10	17 (2.4)	23 (1.6)
11–15	20 (2.9)	32 (2.2)
16–19	14 (2.0)	19 (1.3)
20–25	11 (1.6)	26 (1.8)
26–34	42 (6.0)	134 (9.2)
35–44	223 (31.8)	545 (37.6)
45–54	230 (32.8)	429 (29.6)
55–64	70 (10.0)	162 (11.2)
> 65	26 (3.7)	53 (3.7)
Preferred not to say	4 (0.6)	0 (0)
Did not answer	37 (5.3)	17 (1.2)
Sex	($n = 701$)	($n = 1451$)
Female	538 (76.7)	1139 (78.5)
Male	110 (15.7)	269 (18.5)
Other (please specify)	2 (0.3)	7 (0.5)
Preferrred not to say	8 (1.1)	36 (2.5)
Did not answer	43 (6.1)	0 (0)
Region	($n = 701$)	($n = 1451$)
East Midlands	26 (3.7)	101 (7.0)
East of England	39 (5.6)	99 (6.8)
London	84 (12.0)	138 (9.5)
North East	27 (3.9)	44 (3.0)
North West	74 (10.6)	115 (7.9)
Northern Ireland	15 (2.1)	22 (1.5)
Other (please specify)	39 (5.6)	97 (6.7)
Scotland	32 (4.6)	256 (17.6)
South East	124 (17.7)	153 (10.5)
South West	83 (11.8)	127 (8.8)
Wales	18 (2.6)	96 (6.6)
West Midlands	49 (7.0)	101 (7.0)
Yorkshire and the Humber	49 (7.0)	74 (5.1)
Did not answer	42 (6.0)	28 (1.9)
Ethnicity	($n = 701$)	($n = 1451$)
Asian/Asian British	37 (5.3)	36 (2.5)
Black/African/Caribbean/Black British	5 (0.7)	20 (1.4)
Mixed/multiple ethnic groups	11 (1.6)	40 (2.8)
Other (please specify)	6 (0.9)	16 (1.1)
White	576 (82.2)	1275 (87.9)
Preferred not to say	23 (3.3)	42 (2.9)
Did not answer	43 (6.1)	22 (1.5)

*Indicates that some partipants have double roles to explain larger N.

Priority 3: How should we best manage emotional well-being in children and young people with neurological conditions?

Twenty-one original uncertainties for this question included the management of fatigue and challenging behaviour in children with acquired brain injury, the management of anxiety in children with CP, and cognitive behavioural therapy for functional neurological disorders. There is no good-quality evidence for specific interventions in these groups. There was overlap with other questions in the long list of 26 questions taken to the final workshop regarding epilepsy (ranked 12) and children with immune-mediated neurological disorders (ranked 21) (Table S2). Only 4 of 24 studies included CYP in a Cochrane systematic review and meta-analysis of the impact of psychological treatments for people with epilepsy on health-related quality of life in CYP.[18]

Priority 4: What are the most effective strategies to support communication in children and young people with neurological conditions, for example, use of high-technology and low-technology augmentative alternative communication, or improving speech intelligibility?

Six original uncertainties were related to a range of speech and language therapy approaches. Previous Cochrane reviews into speech therapy interventions for children with CP and Down syndrome respectively reported on the clinical heterogeneity of participants, interventions, and outcome measures, and included small unblinded studies.[19,20]

TABLE 2 Organizing the uncertainties from survey 1.

Conditions	All	After screening	Refining the questions and evidence checking	Steering group discussion to create structured questions for the second survey
Epilepsies	174	37	14	
No specific condition or comorbidities	176	25	8	
Motor and movement disorders	262	88	18	
Neonatal conditions	55	13		
Infection and inflammation	907	64		
Inherited white matter disorders	2	0		
Neurocutaneous disorders	20	5		
Neurodevelopmental disorders	45	0		44[a]
Neuromuscular disorders	16	6	21[a]	
Headache	40	13		
Functional neurological disorders	18	3		
Other	59	30		
Stroke	15	12		
Transient loss of consciousness	11	1		
Total	1800	297	61	

[a]Some original uncertainties for rarer conditions were combined and themed to align with wider questions about more common conditions; thus, many questions were universal across different condition categories.

TABLE 3 The top 10 research priorities.

Priority number	Question
1	Can early therapy interventions improve functional and developmental outcomes in infants experiencing brain injury during pregnancy or infancy?
2	What are the most effective interventions to support sleep in children and young people with neurological conditions?
3	How should we best manage emotional well-being in children and young people with neurological conditions?
4	What are the most effective strategies to support communication in children and young people with neurological conditions, for example, use of high-technology and low-technology augmentative alternative communication, or improving speech intelligibility?
5	What are the most effective medical and non-medical treatments to manage distressing symptoms (e.g. pain, irritability) in children and young people suffering life-limiting neurological conditions?
6	What are the safest and most effective antiseizure medications for seizures in newborn infants (up to 28 days)?
7	Which medications should be used, and in what sequence, in the management of muscle stiffness (hypertonia) in children and young people?
8	Are medications (e.g. antibiotics or immunological treatments) effective in the management of paediatric acute-onset neuropsychiatric syndrome and paediatric acute-onset neuropsychiatric disorders associated with streptococcal infection)?
9	Which psychological interventions are most effective in children and young people who have functional neurological disorders?
10	What are the best non-medical interventions (including therapies, orthoses, for example, splints, and high-technology and low-technology supports) for children and young people with motor disorders?

Subsequent systematic reviews in both populations revealed more promising findings, but the quality of evidence is low.[21,22]

Published systematic reviews on augmentative alternative communication concluded that sparse evidence exists for several interventions in different populations. A recent review included qualitative studies of parental perceptions of use and highlighted the need for more services that support children with complex communication deficits in different environments, more inclusive school programmes (promoting meaningful engagement with peers), more functional use of augmentative alternative communication systems in real-world situations, and service support over an extended time period.[23]

Priority 5: What are the most effective medical and non-medical treatments to manage distressing symptoms (e.g. pain, irritability) in children and young people suffering life-limiting neurological conditions?

Three original uncertainties were about pain in common conditions such as CP and irritability in a rare condition (Batten disease). Children with life-limiting CNCs experience symptoms (such as pain) that are challenging to recognize and manage (presenting in different ways such as distress or self-injurious behaviours, i.e. uncontrollable head banging, face slapping, tongue biting, and self-mutilation), and impact their quality of life, as well as the quality of life of their whole family and caregivers, yet there is little evidence to guide professionals on the best treatments. Pain has been extensively studied; systematic reviews regarding pharmacological interventions in infants and children with, or at risk of CP, showed either limited or contradictory evidence because of the heterogeneity of the studies or weak study designs and limited use of validated outcomes.[24–27] A comprehensive update on a review on psychological therapies on pain, depression, and anxiety found positive effects in decreasing the frequency and intensity of pain for those suffering headache and mixed chronic pain post-treatment. However, most studies regarding pain in other CNCs, or those addressing depression or anxiety, showed generally unclear results, high risk of bias, low-quality evidence for the outcomes, and sparse data.[28,29]

Priority 6: What are the safest and most effective antiseizure medications for seizures in newborn infants (up to 28 days)?

Four similar uncertainties were consolidated into this question. Based on a comparative study with phenytoin published in 1999, the first-line treatment for neonatal seizures remains phenobarbital, even with the risk of neurotoxicity.[30] The NEOLEV2 study showed that phenobarbital gave better seizure control than levetiracetam in a small group of infants; however, adverse events were greater in the group treated with phenobarbital.[31] Subsequent systematic reviews concluded that there had been very few comparative pharmaceutical trials for antiseizure medications in infants, and that studies lacked blinding and randomization. There has been inconsistent use of electroencephalography to confirm seizures in infants and there is no consensus on second-line agents. There is also a lack of meaningful longitudinal studies relating neonatal seizure control to developmental outcome.[32–34]

Priority 7: Which medications should be used, and in what sequence, in the management of muscle stiffness (hypertonia) in children and young people?

There were 17 original uncertainties regarding the comparative efficacy and side-effect profile of medications used in spasticity and dystonia. There is a lack of robust evidence base for medications widely used for hypertonia and dystonia in childhood and there is significant variation in UK practice.[35] Many of the medications used have significant side effects, such as sedation, respiratory depression, and gastrointestinal dysfunction. An updated systematic review of the pharmacological and neurosurgical management of children with CP included 46 studies (four randomized controlled trials), including 915 children, with various interventions. There was low-quality evidence in favour of clonidine with regard to dystonia and goal achievement, and adverse events with clonidine and trihexyphenidyl.[36] This has informed the American Academy for Cerebral Palsy and Developmental Medicine clinical guidance for the treatment of dystonia in CP.[37] A systematic review of cannabinoids for spasticity included five paediatric studies, but only one randomized control trial, showing no significant reduction in spasticity compared to placebo.[38] This question has also been prioritized in the recently published top 10 research themes for dystonia in CP.[39]

Priority 8: Are medications (e.g. antibiotics or immunological treatments) effective in the management of paediatric acute-onset neuropsychiatric syndrome and paediatric acute-onset neuropsychiatric disorders associated with streptococcal infection)?

Multiple duplicates and similar uncertainties were refined to focus on pharmacological treatments for these conditions. Several treatment options and strategies have been proposed to treat paediatric acute-onset neuropsychiatric syndrome and paediatric acute-onset neuropsychiatric disorders associated with streptococcal infection, yet there is no consensus or a clear evidence base. The most comprehensive systematic review regarding obsessive-compulsive disorder in paediatric acute-onset neuropsychiatric syndrome and paediatric acute-onset neuropsychiatric disorders associated with streptococcal infection evaluated 11 studies including 473 patients. There was no statistically significant benefit of either surgical or medical intervention. Variable outcomes were described because of consistency in the medication used and the timing of administration.[40] Similar conclusions were also drawn from a systematic review of anti-inflammatory, antibacterial, and immunomodulatory treatments, which revealed the methodological diversity of studies, no clear evidence of efficacy, but risk of adverse events from the interventions.[41]

Priority 9: Which psychological interventions are most effective in children and young people who have functional neurological disorders?

Two original uncertainties were submitted. The symptoms of functional neurological disorders are diverse and vary

between patients, often necessitating a multidisciplinary approach. Symptoms can include changes in consciousness, speech, sensation, and movements of the body, which are not better explained by a physical condition and yet cause significant impairment in day-to-day functioning. There is limited understanding of the aetiology of this condition, but intervention approaches have been explored.[42] A wide search of the literature showed that psychological treatments, such as retraining and control therapy, other cognitive behavioural therapies, and multidisciplinary rehabilitation, have been evaluated;[43] however, no systematic reviews were found relating to psychological interventions in functional neurological disorders. High-quality studies to evaluate such interventions are needed.

Priority 10: What are the best non-medical interventions (including therapies, orthoses, for example, splints, and high-technology and low-technology supports) for children and young people with motor disorders?

Thirty-four initial uncertainties covered both specific and combined therapies, orthoses, and high-technology and low-technology equipment in many different CNCs and populations. Since 2013, the focus of the British Academy of Childhood Disability–JLA PSP has been to review the evidence base and improve the quality of future research.[44] The systematic review last updated in 2019 on the Novak 'traffic light' state of the evidence mapped the therapeutic interventions offered and their evidence base.[45] There is now clearer evidence regarding interventions, such as constraint-induced and bimanual approaches to support upper-limb function in children with unilateral CP,[46–49] but the quality of evidence for other populations, for example, non-ambulant children with complex comorbidities, is low, with paucity of well-designed clinical trials.[50–52] There is lack of consensus regarding the use of orthoses and higher-technology supports (such as virtual reality, video games, and robotics) because of small-scale pilot studies and inconsistent trial design.

DISCUSSION

We set out the top 10 research priorities as developed through an NIHR–JLA PSP for interventions in CNCs. These cover a wide range of interventions and conditions because of the wide scope of the PSP. Some are disease-specific, others (priority 2: sleep; priority 3: emotional well-being; priority 4: communication difficulties and disorders; priority 5: distressing symptoms) apply to almost all CNCs, making this a hugely inclusive study.

Many uncertainties submitted by participants of survey 1 were related to epidemiology, pathophysiology, prevention of neurological disorders, service delivery, and health care resources. These were out of scope and were not taken forward to survey 2; however, they provide valuable insight to inform future PSPs, as well as services for neurological disorders offered by health, education, and social care providers in the UK. Identification of such priorities will allow us to focus on unmet needs within research.

The British Academy of Childhood Disability published their JLA PSP in 2015.[44] This has been used in successful funding applications, and there are now multiple ongoing studies in childhood neurodisability.[53] However many of their priorities are unanswered, and there is direct overlap with our JLA–BPNA top 10 priorities regarding sleep, therapeutic interventions, orthoses, and emotional well-being. With the current results of this PSP, we will endeavour to collaborate and continue to seek answers to the uncertainties highlighted.

Challenges with designing good-quality research studies and obtaining appropriate funding in complex populations may explain the lack of evidence base for all these priorities. There is clinical heterogeneity inherent to almost all CYP with CNCs because of differing underlying aetiologies and variation in symptoms, severity, and age at presentation. Unavoidable variance in environmental, sociodemographic, and family factors can have a significant impact on accessibility to interventions and outcomes. Many confounding interventions are often offered simultaneously to CYP with CNCs and there is limited consensus on the best outcome measures and timing of follow-up. Pragmatic approaches to trial design, and intervention delivery, which factor in the family and home environment, are required.

Historically, research priorities in CNCs have been set by expert health care providers, researchers, and commercial organizations, with little or no involvement from patients, their families, or the general public. The rapidly increasing availability of new and expensive therapies for many genetic conditions risks the agenda of research being driven by the pharmaceutical and biotechnology industries. The involvement of patients, caregivers, and members of the public as partners in research provides measurable benefits that improve the utility and conduct of research, with positive impacts on the people involved.[54]

Any PSP has inherent limitations. Engaged stakeholders, who have greater socioeconomic or time resources, have a stronger voice than those with fewer resources. There was representation from strong third-sector organizations, and parents and caregivers of CYP with rarer conditions, which are included in the top 10. There was a delicate balance to negotiate between prevalence, severity, and family impact of a condition. The information team and steering group were careful to ensure inclusion of questions regarding very rare conditions as well as wider questions on more common conditions, particularly when merging multiple uncertainties into broader groups (e.g. the question in the final top 10 regarding non-medical interventions for children with motor disorders), or addressing comorbidities (e.g. sleep and emotional well-being). Despite a methodology that includes all stakeholders, professionals, third-sector organizations, and families, it is not possible to determine if all groups were reached, or the reasons why some groups and individuals

chose not to take part. Mothers of CYP with CNCs were best represented. The purposive sampling in the final workshop was as transparent as possible and the steering group worked hard to get equity of representation for all stakeholder groups. Care was also given to balancing professionals with inherent enthusiasm for their respective subspecialty.

Through a rigorous process involving patients, caregivers, and clinicians as key stakeholders, we identified key research uncertainties regarding interventions for CYP with CNCs. These include the top 10 priorities to inform researchers in developing specific and answerable questions for funding applications, and drive meaningful research to ultimately improve clinical care for children with neurological conditions.

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DATA AVAILABILITY STATEMENT

There are no individual participant data that underlie the results reported in this study. Any primary data from the uncertainties after deidentification from respondents from all stages of the PSP process can be shared up to 5 years after the publication of the article with researchers who provide a methodologically sound proposal for any purpose. Proposals should be directed to philip.levine@bpna.org.uk; to gain access, researchers requesting data will need to sign a data access agreement.

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SUPPORTING INFORMATION

The following additional material may be found online:
Table S1: Rankings for each group from survey 2.
Table S2: Final rankings of 26 from workshop.
Appendix S1: Supplementary method.
Appendix S2: Charities and organizations approached.

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