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Original Research

Cerebral Palsy Research Network Clinical Registry: Methodology and Baseline Report

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KEYWORDS
Cerebral palsy;
registries;
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Abstract *Objective:* To apply practice-based evidence to clinical management of cerebral palsy (CP). The process of establishing purpose, structure, logistics, and elements of a multi-institutional registry and the baseline characteristics of initial enrollees are reported.
Design: A consensus-building process among consumers, clinicians, and researchers used a participatory action process.
Setting: Community, hospitals, and universities.
Participants: More than 100 clinicians, researchers, and consumers and more than 1858 enrollees in the registry.
Main Outcome Measures: Not applicable.
Results: Consensus was that the purpose of registry was to (1) quantify practice variation, (2) facilitate quality improvement (QI), and (3) perform comparative effectiveness research (CER). Collecting data during routine clinical care using the electronic medical record was

List of abbreviations: CDE, common data element; CER, comparative effectiveness research; CP, cerebral palsy; CPRN, Cerebral Palsy Research Network; EHR, electronic health record; GMFCS, Gross Motor Function Classification System; HCRN, Hydrocephalus Clinical Research Network; IRB, Institutional Review Board; LFEP, Learn from Every Patient; NCH, Nationwide Children's Hospital; NINDS, National Institute of Neurological Disorders and Stroke; PT, physical therapy; OT, occupational therapy; QI, quality improvement; REDCap, Research Electronic Data Capture; SLP, speech language pathology; VON, Vermont Oxford Network.

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determined to be a sustainable plan for data acquisition and management. Clinicians from multiple disciplines defined salient characteristics of individuals and interventions for the registry elements. The registry was central to the clinical research network, and a leadership structure was created. A leading electronic health record platform adopted the registry elements. Twenty-four sites have initiated the data collection process and agreed to export data to the registry. Currently 12 are collecting data. Number of enrollees and characteristics were similar to other population registers.
Conclusions: This is the first multi-institutional CP registry that contains the patient and treatment characteristics needed for QI and CER. The Cerebral Palsy Research Network registry elements are implemented in a versatile electronic platform and minimize burden to clinicians. The resultant registry is available for any institution to participate and is growing rapidly.

Cerebral palsy (CP) as a group of disorders represents the largest cause of physical disability of childhood onset.[1] Globally, there is estimated to be more than 17 million individuals with CP aging from infancy to older than 90 years.[1] Given the heterogeneity in severity and etiology, clinical practice guidelines are not clearly defined and often do not yield optimal results.[2] It is obvious to providers and consumers that current knowledge and interventions targeting issues of individuals with CP across the lifespan are inadequate.

In 2014, the National Institutes of Health hosted a workshop entitled "State-of-Science and Treatment in Cerebral Palsy" to examine critical gaps in evidence and treatment of individuals with varying forms of CP.[2] More than 70 participants represented a spectrum of stakeholders including clinicians, basic science researchers, epidemiologists, CP patient advocacy organizations, individuals with CP, and caregivers. Consideration of basic and clinical research by this group highlighted numerous knowledge gaps and, in particular, a clear need for detailed information about types, timing and intensity of interventions, and patient factors associated with the best outcomes over time.[2]

A barrier to bridging knowledge gaps is the lack of systematically collected prospective data about individuals with CP and the interventions they receive, which can be collected in a clinical registry.[3] Practice-based evidence methodology collects salient clinical and patient data to identify patterns of care that work for individuals with similar characteristics.[4] It has been used successfully in other complex conditions, such as traumatic brain injury.[5] A registry of children with CP and their care could also be used for longitudinal studies to inform clinical management of CP in adulthood.

The workshop attendees reviewed the effect of existing registries established in Australia, Canada, and Sweden on knowledge about epidemiologic factors among individuals with CP.[6] The workshop attendees identified the critical need for a clinical registry to be established in the United States to facilitate comparative effectiveness research (CER) and quality improvement (QI).[1]

Clinicians, researchers, and consumers at the workshop and from the broader North American community formed a work group to pursue the creation of a multi-institutional clinical registry based on practice-based evidence methodology. The purpose of this article is to describe development of the purpose, structure, and elements of a multi-institution clinical CP registry and provide a baseline report of initial enrollees.

Methodology

Study design

A consensus-building process that followed a participatory action research framework was used to build agreement among clinicians, researchers, and consumers. Cross sectional information provided descriptive information about enrollees as of December 2019.

Participants

A cohort of more than 150 individuals participated in the development of the registry from January 2015 to July 2016. More than 50 clinicians and researchers were involved in conference calls over months to define registry elements, and $>$ 100 consumers, clinicians, and researchers attended webinars, meetings, and online surveys to provide input and feedback.

This observational study is minimal risk; hence, a waiver of consent was obtained from the Institutional Review Board (IRB) at Nationwide Children's Hospital (NCH). NCH maintains a master IRB to which several sites have submitted a reliance agreement; other institutions have approval from their local IRBs. Including all patients who attend clinics at each institution limits bias.

Data analysis

The consensus-building process was iterative and described below. Frequencies using the total registry enrollment as the denominator were calculated for enrollee characteristics.

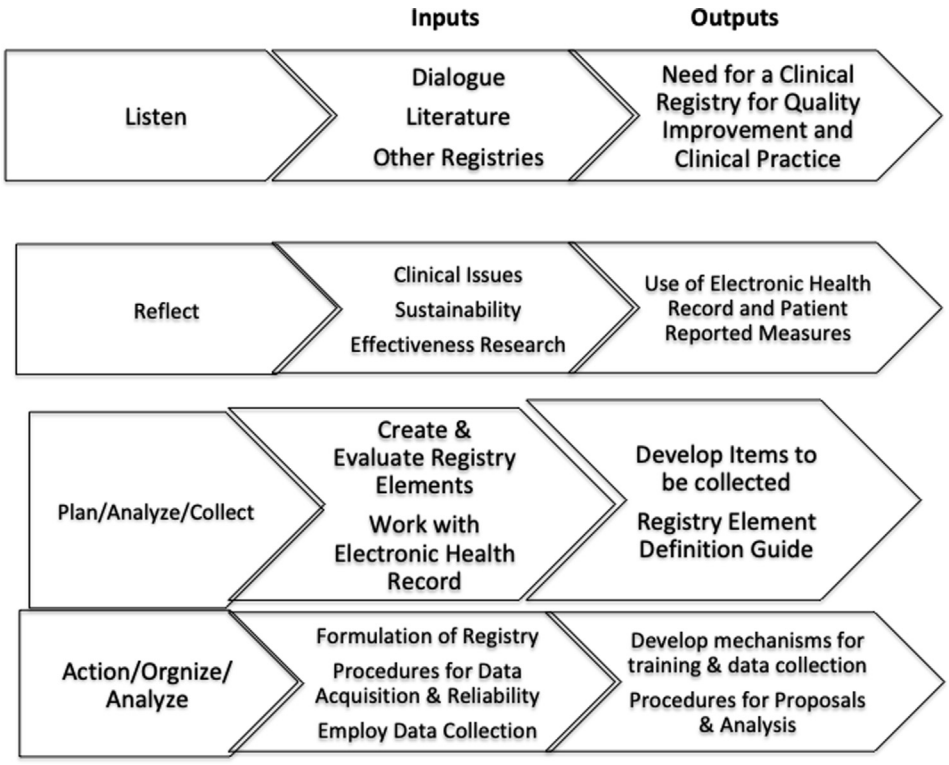

Fig 1 Process of registry development using participatory action framework and standards for clinical research.

Results

Consensus-building process

Activities paralleled a participatory action research process.[7] The steps involved were to listen, reflect, plan/analyze, and take action (fig 1). Additionally, Clinical Data Interchange Standards Consortium Operational Data Model (https://www.cdisc.org/standards) outlines a similar process (plan, collect, organize, analyze) for the development of clinical registries.

The intention of the listen phase was to gather feedback on the purpose, structure, and content of the clinical registry. Researchers, clinicians, and consumers were involved in an iterative process of consensus building through phone calls, webinars, face-to-face meetings, and online surveys led by Paul Gross, an Advisory Council member of the National Institute of Neurological Disorders and Stroke (NINDS). Information was disseminated at professional meetings, and input and support were gathered. Connections with CP advocacy groups linked parent representatives and individuals with CP to the process.

All agreed the clinical registry should use the electronic health record (EHR) to quantify practice variation, facilitate QI initiatives, and support hypothesis generation for clinical research and track outcomes using the International Classification of Function across the lifespan.

The reflect phase allowed participants and/or stakeholders to review existing national and international registries for CP and other rare diseases for (1) their content (both to fill knowledge gaps and allow comparability); (2) whether and how they interfaced with consumers and clinicians; and (3) for successful examples of sustainable business models. Information technology solutions were sought to allow for flexibility to modify data elements over time and to leverage multiple EHR platforms. The Vermont Oxford Network (VON),[8] a neonatal intensive care registry, was identified as an exemplar QI effort, and the Hydrocephalus Research Network (HCRN),[9] a pediatric neurosurgery network, was identified as an exemplar combined QI and clinical research effort. The Childhood Arthritis and Rheumatology Research Alliance,[10] the ImproveCareNOW registry (an inflammatory bowel disease network),[11] and the T1D Exchange (a type 1 diabetes registry),[12] provided examples of various ways to capture both clinical and patient-reported data. Consensus emerged that the current registries that include CP did not adequately address the need for enabling QI and CER.

Federally funded health research agencies in North America such as the National Institutes of Health and the Center for Disease Control did not fund registry infrastructure.[13] Exemplar cases, the VON and HCRN, differ in both business models and amount of data collected. Membership in the VON required a participation fee. Fewer data points were collected in the VON compared with HCRN, but VON organized annual quality conferences. Membership in the HCRN required administrative support from each participating hospital and multiple philanthropic funding streams.[9]

NCH's Learn from Every Patient (LFEP) CP registry had been in use for several years. The LFEP had been shown to be effective in improving care.[14] Data were collected as a part of routine clinical care through Epic EHR forms,

Table 1 Institutions and electronic health platforms

Electronic Health Platform	Institution
Epic	Al duPont Hospital for Children
	Children's Hospital Colorado
	Seattle Children's Hospital
	Texas Children's Hospital
	Texas Scottish Rite Hospital
	University of California Los Angeles
	University of California San Diego-Rady's Children's
	University of California San Francisco-Benioff
	University of Florida-Jacksonville
	University of Michigan Medical Center
	University of North Carolina-Chapel Hill
	University of Virginia
	Yale University, School of Medicine, Yale New Haven Hospital
Cerner	
	Boston Children's Hospital
	Gillette Specialty Care
	Primary Children's Hospital
	Riley Children's Hospital
Allscripts	
	Children's of Alabama
	Phoenix Children's Hospital
	University of Texas Health-Houston

created by the clinicians to capture discrete data for clinical, research, and QI use. Using Epic decreased time burden for documentation by clinicians and eliminated duplicate data entry into the registry.

Existing CP specific registries focused on risk factors and prevalence or provided a vehicle for recruitment for research projects.[15,16] Some registries included information about schools and families,[17] had specific medical information (genetic mapping),[18] or had patient-reported outcomes.[10] There was a need for a registry that collected both clinical and patient-reported information.

The plan/analyze/collect phase established consensus on which discrete elements to include. Development of registry elements was a consensus-building,[19] iterative process involving multiple stakeholders. Four disciplinary work groups were established to define the items to be included: (1) nonsurgical physicians (developmental pediatricians, physiatrists, neurologists); (2) orthopedic surgeons; (3) neurosurgeons; and (4) physical, occupational, and speech therapists (see https://cprn.org/network/). Garey Noritz led the nonsurgical group, and Amy Bailes led the physical therapy (PT)/occupational (OT)/speech language pathology (SLP) group. Unni Narayanan and Jerry Oakes led the orthopedic surgery and neurosurgery work groups, respectively. Disciplinary work group leaders recruited participants for each group yielding 9 orthopedic surgeons, 9 neurosurgeons, 8 PT/OT/SLP members, and 11 nonsurgical physicians. An adult work group of 14 members was created to vet all items for applicability across the lifespan led by Mary Gannotti and Deborah Thorpe.

Each disciplinary group was asked to provide expert opinion about key characteristics[20] of individuals and interventions that influenced decision making and/or outcomes in CP. Susan Horn, biostatistician, attended calls to assure that the registry elements included essential data elements that affect intervention effectiveness, limited to what would be collected during usual clinical care. The purpose, structure, and registry elements were disseminated in professional meetings; hospital in-services and/or conference calls, webinars, recorded meetings, posted blogs, and minutes were posted throughout the process.

The nonsurgical physician group started with a line-by-line review of the 83 elements in the NCH LFEP registry. Clinicians then added data elements from medical history and clinical examinations that the group considered critical to treatment decisions and outcomes for patients with CP. The final list was vetted for importance and consistency of collection across participating centers. Discipline-specific measures were noted. The PT/OT/SLP work group began by generating the data elements that would be collected in multidisciplinary clinics rather than from individual treatment sessions. The members of the work group shared tables of clinical measures believed to be reliably captured in annual clinic visits and relevant to outcomes. It was agreed that the registry would not be prescriptive about measures or scales but allow the clinicians to use the scale that suited their need, capturing variations in practice. For example, tone could be measured using Ashworth Scale, Modified Ashworth Scale, or Tardieu Scale. These tables were merged, consolidated, and discussed to achieve consensus. A set of parent- and/or patient-reported therapy questions was created to gather information about recent use of equipment and therapy services, including location of service.

The neurosurgeon work group focused on 2 surgical procedures, intrathecal baclofen pump implantation and selective dorsal rhizotomy. A checklist of clinical patient and physical examination data deemed necessary for

Table 2 Demographic and clinical characteristics (N = 1858)

Demographic and Clinical Characteristics	Percent of Registry
Age Group	%
0-2	3
3-5	17
6-10	34
11-18	31
19-25	10
26-35	2
36+	1
Total	100
Missing	3
Sex	%
Female	45
Male	55
Unknown	0
No information	0
Null	0
Missing	0
Race	%
American Indian or Alaska Native	1
Asian	4
Black or African American	14
Native Hawaiian or Other Pacific Islander	1
White	60
Multiple race	7
Refuse to answer	3
Unknown	3
No information/Not reported	2
Missing	4
Ethnicity	%
Not Hispanic or Latino	85
Hispanic or Latino	11
Other	0
No information	3
Unknown	1
Insurance	%
Commercial	35
Medicaid	62
Medicare	3
Etiology	%
Hypoxic ischemic encephalopathy	11
Prematurity: intraventricular hemorrhage	9
Prematurity: periventricular leukomalacia	11
Prematurity: white matter injury	2
Prematurity: multiple injuries	2
Congenital infection	2
Congenital stroke	4
Brain malformation	7
Unknown	18
Genetic condition	2
Mixed	12
Other	9
Missing	11
Gestational Age	%
≤ 27 wk	18
28-31 wk	12
32-36 wk	17
≥ 37 wk	39
Missing	14
Topography	%
Unilateral	16
Bilateral symmetric	69
Triplegia	10
Missing	5
Seizures	%
Yes	35
No/only in the past	58
Missing	7
Feeding tube	%
By mouth	62
Any tube	27
Missing	11
Pain	%
Yes	15
No	74
Missing	11

decision making and planning purposes collected at the initial assessment(s) and preoperative visits, procedural and/or intraoperative details, and postoperative data were used as a starting point for building consensus.[21] Group members contributed data elements from their own practice. Minimizing the documentation burden for the clinicians was a priority. The item list was reviewed and revised until consensus was achieved.

The orthopedic work group began by stratifying their list of data elements based on the surgical goals influenced by the patient's Gross Motor Functional Classification System (GMFCS) level. For nonambulatory patients (GMFCS IV and V) the work group focused on hip interventions and adopted the case report forms that had been developed for an international multi-institution cohort study of hip interventions in CP[22,23] as a starting point. For ambulatory patients (GMFCS I-III) the group focused on data elements pertinent to gait improvement—related interventions. The work group also reviewed data fields collected in the CP registry at the AI duPont/Nemours Children's Hospital. Review of these 2 study databases yielded consensus on a set of data fields critical to the orthopedic interventions for children with CP. Given the number of possible orthopedic procedures, the work group decided to limit their focus to interventions of the lower extremities and to leave upper extremity and spinal interventions for future enhancements of the registry.

After the initial efforts of each work group were assimilated, each disciplinary work group reviewed the other groups' item sets to provide feedback and for harmonization of items. The registry elements contains 671 data items, organized by 4 disciplinary areas. A complete set of web forms using Research Electronic Data Capture (REDCap), a formal data dictionary for registry elements, and a visual representation of the planned data collection

Table 3 Preliminary report: additional clinical characteristics (N = 1858)

Functional Classification Systems and Impairments	Percent of Registry
Gross Motor Functional Classification Scale Level	%
I	25
II	16
III	11
IV	18
V	27
Not assessed	1
Missing	3
Manual Ability Classification System	%
I	9
II	11
III	9
IV	9
V	9
Not assessed	8
Missing	46
Communication Function Classification System	%
I	16
II	7
III	5
IV	11
V	7
Not assessed	12
Missing	42
Visual impairment	%
Normal	25
Impaired	34
Blind	1
Missing	41
Hearing impairment	%
Normal	51
Impaired	7
Deaf	0
Missing	42
Constipation	%
Yes	16
No	19
Missing	66

was created (supplemental appendix S1, available online only at http://www.archives-pmr.org/).

The action/organize/analysis phase launched the clinical registry based on prior output. The variety of stakeholders and multiple forms of iterative communication ensured the validity of the process.[19] Data validity is further insured by the development of the Registry Element Guide with element definitions, Standard Operating Procedures for Data Collection, Extraction, Proposal Development, and training for onboarding sites (cprn.org).

In the spring of 2015, the Cerebral Palsy Research Network (CPRN) was established at the University of Utah, an Executive Committee was formed, and funding was secured. Applications were made to IRBs, and Business Associate Agreements were initiated between institutions and the University of Utah.

In July 2016, the CPRN registry elements was released via "Smart Data Elements" in a series of Epic system updates. The clinicians document findings by clicking on appropriate buttons and checkboxes in a CPRN Epic smart form, which then generates the clinical note. NCH developed 21 Epic smart forms, supporting medical history, examinations, and interventions across 6 disciplines and tested usability in their CP clinic and surgical practices.

In October 2016, registry elements were cross-referenced with the first version of the NINDS CP common data elements (CDEs) to evaluate continuity in content and structure between elements of each. There was an overlap of 221 items between NINDS CDEs and registry elements; 326 did not overlap, partial matches existed for 123. Nonoverlapping elements were information on neurosurgical and orthopedic interventions that have not yet been added to the CDEs. A future version of the registry elements will change the partial matches where appropriate. During the public comment period for the NINDS CP CDEs, the registry elements discipline groups recommended that the NINDS CP CDEs change 6 items and offered its nonoverlapping surgical intervention elements for a future version of the NINDS CP CDEs. The NINDS CP CDE working group revised 3 CDEs as recommended and rejected the other recommendations.

A total of 24 institutions (table 1) across the United States agreed to join CPRN and are in varying stages of obtaining IRB approval, data transfer agreements, and information technology processes to connect Epic forms to the CPRN data elements. At the time of this writing, 12 clinical sites are using CPRN Clinical Registry forms. REDCap forms are available for sites that do not have Epic and are in use by 6 of the 12 sites.

Enrollee characteristics

Data described here were extracted in December 2019 and include all enrollees to that date. Following standard operating procedures for data collection, storage, and extraction, 1858 unique patients have had data entered from CPRN clinical sites. The GMFCS level, age, and topography distribution are comparable with other international registers[6,24] as are the number of participants and their characteristics (tables 2 and 3). Missing data in patient characteristics range from 0% to 66%. Items with more than 14% missing data include the Manual Ability Classification Scale, Communication Functional Classification Scale, presence or absence of visual impairment and hearing impairment, and constipation.

Discussion

A clinical registry to gather practice-based evidence about lifespan care for individuals with CP has been created. The registry element definitions have been published (CPRN.org) as well as the standard operating procedures for joining the network, data collection, project proposal, and analysis. Initial enrollment from the first 18 months demonstrates a robust number of 1858 patients with a variety of

clinical and demographic characteristics. Data are biased to participating sites and patients but have the potential to be large enough to make generalizations about care in the future. Each of the 24 CPRN institutions provide care to around 1000-3000 individuals with CP annually. With potential to increase enrollment to thousands of enrollees in the coming years, this will provide cohorts of hundreds of individuals with similar characteristics from which comparisons can be made.

The CPRN registry element is based on identifying the minimal data set of salient patient characteristics, intervention details, patient and/or parent-reported outcomes, and contextual factors needed to identify patterns of effective care for children with CP. Data elements are focused on clinical characteristics gathered through the history, clinical observation, physical examination, and other tests and interventions. Baseline report demonstrates the capacity of the registry to collect, aggregate, and analyze data in a rapid period of time. With increased enrollment, the registry will be able to address clinically relevant research questions based on current practice.

The CPRN has created a multisite CP registry to collect rich data for clinical research and quality improvement. Because data are captured in the course of regular clinical care, additional data entry is not required. Data are aggregated for analysis at a central site, which allows investigators to access a large, deidentified data set for prospective research. The registry can be used for hypothesis generation and support preliminary data for grant applications. More importantly, a framework has been created by which patients can be recruited from multiple sites for prospective studies with an already existing data infrastructure and data sharing agreements. The size of the registry is already comparable with other international registries.

A major strength of the registry is also a limitation—the fact that clinical sites are not required to enter all data fields on patients to participate in the registry. For example, care at one site may be delivered primarily by a developmental pediatrician, while at others, orthopedists or neurosurgeons may take the lead. A quality improvement study generated from CPRN investigator sites concerning baclofen pump infections and surgical procedures involves only select CPRN sites with neurosurgeons. Consequently, there are not complete data on all patients in the registry from all clinical subspecialties, and there are high rates of missing data on many elements at this time.

The CPRN Clinical Registry is different from other national registries that provide information about incidence, severity,[25] or expenditures.[26] The NINDS CDEs[27] are intended to provide a comprehensive list of data elements to guide and standardize data collection for research protocols and promote meta-analyses. CPRN fills a gap because the registry elements contain salient patient and clinical characteristics to guide best practice. Other disease-specific clinical research registries[10-12] with a similar focus on characterizing a specific diagnostic population and treatment patterns have successfully generated and tested hypotheses, documented practice variation, and assisted producing new knowledge for clinical care.

CPRN has the potential to provide a large sample of diverse participants, ideal for multi-center quality improvement or research projects that use either observational or randomized study designs. Using the EHR provides flexibility for adding and modifying forms in future versions of the registry elements and for integration of patient-reported outcomes. It does not require additional human resources for chart abstraction and minimizes clinician burden.

Study limitations

CPRN has not yet been developed for other EHR systems other than Epic, although other systems are in progress. The alternative, REDCap, is viewed as an interim solution because it requires significant data entry time on top of what is recorded for clinical care.

The efforts to implement the registry were not insignificant. Clinicians have limited time for a volunteer project that entails negotiating support from his/her institution, including the engagement of information technology staff for Epic customization and data extraction. Physicians may need to modify documentation practices to leverage CPRN smart forms. These burdens are offset by clinicians' interest in conducting multicenter research and providing academic opportunities for junior investigators. The flexibility in sites participating in 1 or more of the subspecialty disciplines that serves individuals with CP creates a data set with high rates of missing data. In large sample sizes, missing data of up to 20% can be accounted for statistically. At this time, CPRN registry requires more participants to reach this threshold.

The initial version of the registry elements omitted several areas of CP treatment in an effort to reduce the burden of implementation. These reductions in scope included orthopedic interventions for the spine and upper extremities. Surgical interventions of the lower extremities were the initial focus because these are the most common surgical interventions performed in CP with wide practice variation and limited evidence of effectiveness from high-quality research. Additionally, registry elements pertinent to occupational, speech, and language therapy and nutrition are underrepresented in contrast to PT. PT information is limited also, and a separate project has addressed documenting PT treatment.[28] Nursing has had limited involvement to date and could address issues of the bowel and bladder. Finally, although the registry element includes patient-reported information about frequency of physical and occupational therapy, it does not capture intensity, duration, or focus of therapy. CPRN plans to revise existing elements and add domains such as spine, speech, and PT dose after gaining more experience with clinical and research use of the existing registry.

Conclusions

The creation of a multi-institutional clinical CP registry is feasible. Several clinical sites are actively enrolling patients in the course of regular care. Adoption of the registry

elements by more EHR platforms will enhance the capability for large-scale enrollment across multiple institutions. Future versions of the registry elements will consider documentation of PT services as well as ancillary services important for communication, socialization, feeding, and physical activity. Creation of large sources of data that contain salient information about children, families, and interventions can promote QI and CER for patients with CP. This model could be reproduced for other conditions besides CP and assist with improved quality of care.

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