

## **12.6.20 JPRM Bailes The CPRN becoming a Learning Health Network**

The Cerebral Palsy Research Network: Steps toward building a learning health network for cerebral palsy

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### 1. Introduction

Cerebral palsy (CP) is the most common cause of physical disability in children, with a recent estimated prevalence of 3.5 per 1000 births in the US.(1) (Christensen) CP is associated with high lifetime cost of care of approximately 11.5 billion dollars for all individuals born with CP in 2000.(2) (Honeycutt 2003) Members at a 2014 workshop sponsored by the National Institutes of Health identified a need for a clinical registry for CP in the United States.(3) (Lungu 2016) Different than population-based registries for CP(4-7) (Arneson 2009, Uldall, Anderson, Roberson), clinical registries are not designed to surveil or estimate the prevalence or incidence of CP but utilize data from ongoing care to improve healthcare processes and outcomes, describe patterns of care, reduce variation and conduct research. While there have been clinical registries reported at single medical centers in the US(8-10) (Lowes 2017, Hurley 2011, Hung 2020), the Cerebral Palsy Research Network (CPRN) was established in 2015 across multiple institutions as a means to identify problems, generate solutions and answer questions that cannot be solved at a single institution due to the clinical variability in the population and longitudinal course of CP. The mission of CPRN is to improve outcomes that people with CP value most through high quality clinical research and quality initiatives. A core goal of the CPRN is to establish a large clinical registry by aggregating the individuals seen at these institutions.

Clinical registries utilize electronic health record (EHR) data that is collected as part of usual care. Electronic health record data is a driving force behind the emergence of learning health systems.(11) (Cimino 2007) The learning health system, proposed in 2007 by the National Academy of Medicine(12) (IOM summary 2007,) is defined as any type of healthcare delivery system designed to promote improvement in health and healthcare delivery by integrating care activities of patients, families, clinician researchers and healthcare system leaders. Learning health systems that include multiple institutions engaging all stakeholders to improve the health of individuals with a specific

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condition are called Learning Health Networks (LHNs).(13) (Britto 2018) There are several pediatric LHNs reported in the literature for diseases such as Inflammatory Bowel Disease(14) (Crandall), Pediatric Cardiac conditions(15) (Anderson), and Pediatric Rheumatology care(16) (Smitherman) that have demonstrated improved care and outcomes for these conditions.(17) (Lannon 2013) Features of LHNs include multidisciplinary teams and patient/family partnerships that focus on a high impact condition, use data from ongoing care to provide feedback for learning and improvement, test changes iteratively, support an infrastructure for data collection analysis and reporting, and participate in quality improvement. (Lannon 2013) Clinical registries across multiple institutions are a key part of LHNs(12) (IOM 2007) and are utilized to facilitate clinical care, improvement, and research (Britto 2018). (13)

Creating a LHN is a process that can take several years. Construction of a maturity grid is recommended to assess growth and development towards becoming a learning health network. A recent maturity grid, The Network Maturity Grid (NMG), builds upon literature as well as expert opinion and user experience to provide a structured method to assess network progress and support detailed and strategic discussion.(18) (Lannon 2020r) This tool has a detailed rubric and broad consideration of elements in a LHS. (appendix 1) The purpose of this paper is to report on CPRN's progress toward developing as a LHN and to measure our growth using the NMG tool. The findings will provide detailed information about the strengths, weaknesses, and overall infrastructure of the CPRN, as well as opportunities for improvement.

## **2. Methods**

This descriptive study uses cross-sectional information. Nineteen CPRN leadership team members (executive team, research PIs, or QI project leaders) were invited to participate.

### **2.1. Network Maturity Grid**

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To describe the elements of the CPRN and its development as a LHN, a standardized survey was used. The Network Maturity Grid Tool was developed in 2014 and recently refined in response to feedback and current use by nine established learning networks (Lannon).(18) The rubric consists of six domains with eight to 10 components each. The six domains are “Systems of Leadership”, “Governance and Management”, “Quality Improvement”, “Engagement and Community”, “Data and Analytics”, and “Research”. See Table 1 for a list of components for each domain. Components are rated on a 5-point ordinal scale: 1= not started, 2= beginning, 3= intermediate, 4= mature and 5 = idealized state (See appendix 1). Domain scores are computed as the mean of corresponding component scores. For this review, the study team agreed anything below a score of 3 identified a weakness or area for improvement. After the data was analyzed eight members of the executive committee were asked to prioritize individual components for growth in the next 3-5 years which were then discussed, and consensus was obtained for these priorities.

#### *2.2. Data Analysis*

Data analysis included the use of radar mapping. A radar map is a visual display of multivariate data in the form of a two-dimensional chart. Three or more quantitative variables are represented on axes starting from the same point. Radar maps allow for a quick way to visualize data points in relationship to each other (Thaker 2016, Kaplan 2015).(19, 20) The distance of the variable score from axis represents performance (scores range from a 1 = not started to 5 representing an idealized state). The radar chart tool in Microsoft Excel (version 2013), was used to display total domain scores as well as individual component scores within each domain.

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Domains and Components of Each Domain

Systems of Leadership	Governance and Management	Quality Improvement	Engagement and Community Building	Data and Analytics	Research
Leadership System	Network Management	Network framework for improvement	Expectation that parents, patients, clinicians and researchers are co-creators and co-producers	Data Collection	Research training
Common Purpose	Membership Policy( guidelines, rights and obligations of members)	Quality Improvement projects based on strategic plan	Feedback from patient community	Data Quality and Validation	Research prioritization (connect stakeholders to science)
Understanding of the Organization as a system	Financial sustainability- Business Plan	QI learnings by Network participants shared with other practices	Communication to increase awareness of the Network, opportunities for and importance of engaging in it.	Consent Management	Protocol development and review
Family of Measures	Stakeholder Participation in Governance	Methods for dissemination and spread of key learning across care centers	Competency in co-production and leadership	Data capture and transfer from electronic health record	Trial recruitment tools
Information from Stakeholders	Institutional Review Board policies and protocols	QI reports	Facilitating stakeholder collaboration	Data Standardization and interoperability (with registry or database)	Primary data collection
Strategic Planning for Improvement of the Network	Network Policies and Procedures for intellectual property and data sharing	QI education and training	Patient reported data	Complete Data (linking registry and databases)	Secondary data analyses
Managing Improvement Efforts	Collaboration policy external to the Network (e.g. sponsors, industry)	Communication and publication of QI activities	Patient access to the registry or network data base	Data exploration	Observation and comparative effectiveness studies
	Accessibility to knowledge and tools, and by network participants	Data transparency		Clinician clinical decision support	Clinical trials
	Logistical support for research				N of 1 studies
					Research contributing to the science of improvement

### 3. Results

Thirteen network pediatric leaders (68%) responded, which included two advocates, three physical therapists, one health services researcher, two neurologists, two neurosurgeons, one physiatrist, one

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orthopedist, and one developmental pediatrician. Overall mean scores across domains are displayed as a radar chart in Figure 1 and ranged from a highest score of 3.2 in the “System of Leadership” domain to the lowest score of 2.4 in the “Quality Improvement” domain.

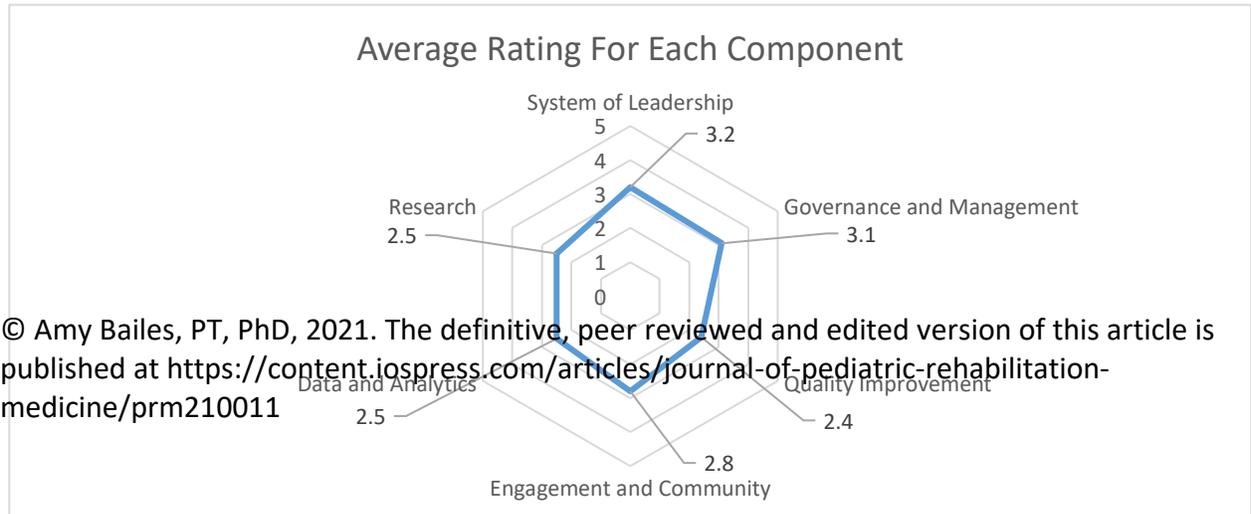
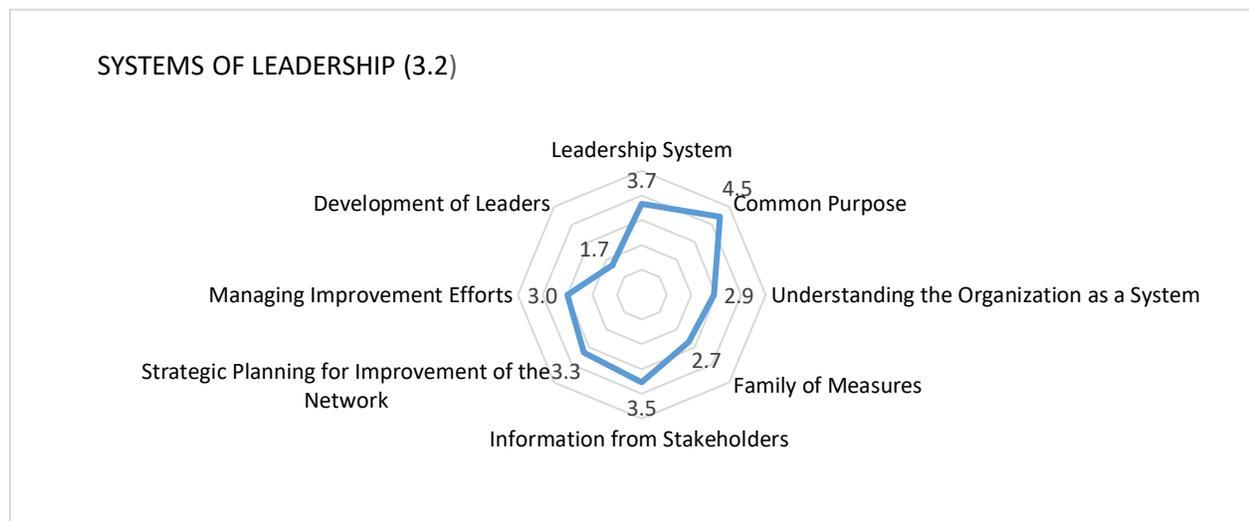


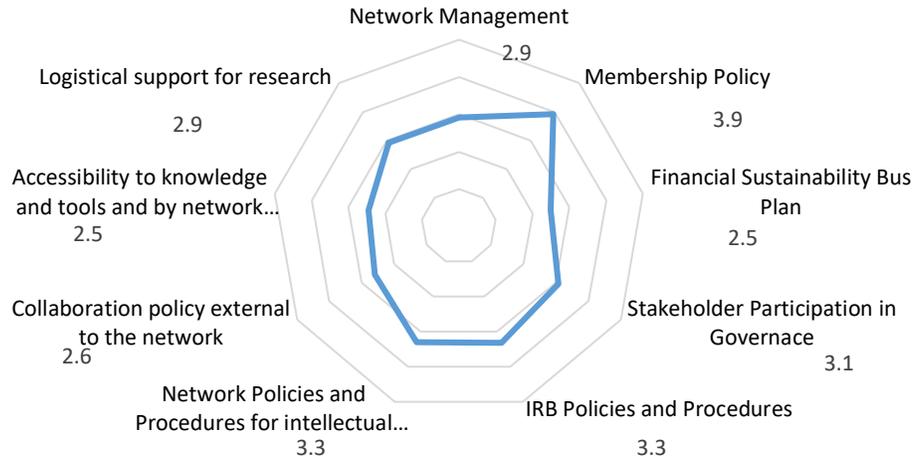
Figure 1 Average Rating for Each Component Across Respondents

Individual component scores within each domain are displayed as radar charts in Figure 2 and from highest score to lowest in Table 2. Nineteen components scored 3 or above, while 31 components scored below 3. No components scored the highest score of 5 or ‘idealized state’. The highest scoring component was “common purpose” of the network, with an average of 4.5/5 and the lowest scoring component was “Clinician clinical decision support” with an average score of 1/5

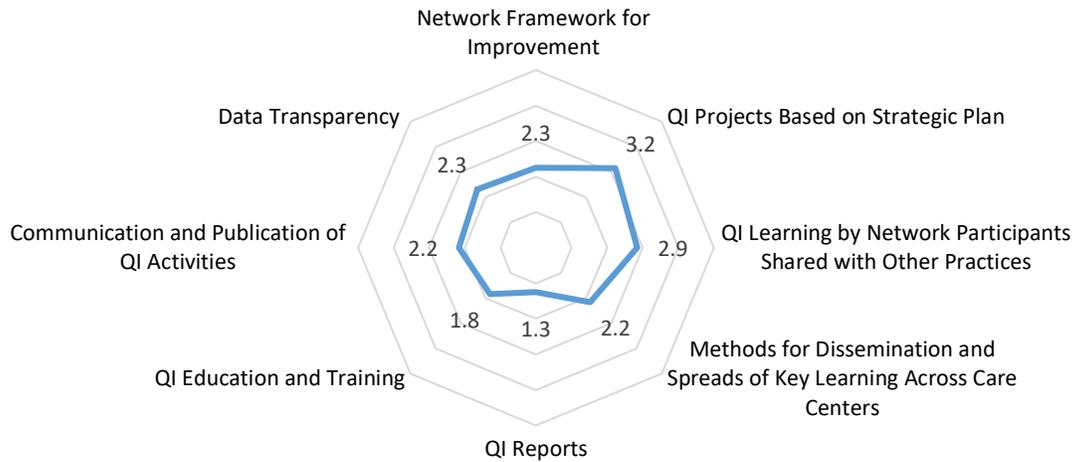


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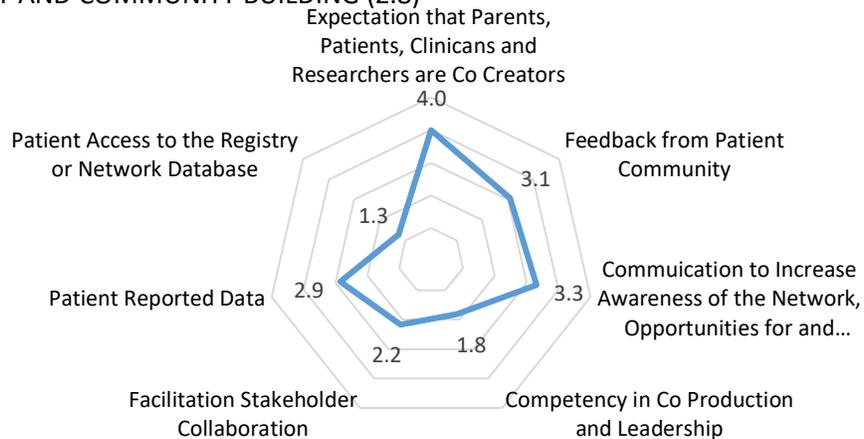
### GOVERNANCE AND MANAGEMENT (3.1)



### QUALITY IMPROVEMENT (2.4)

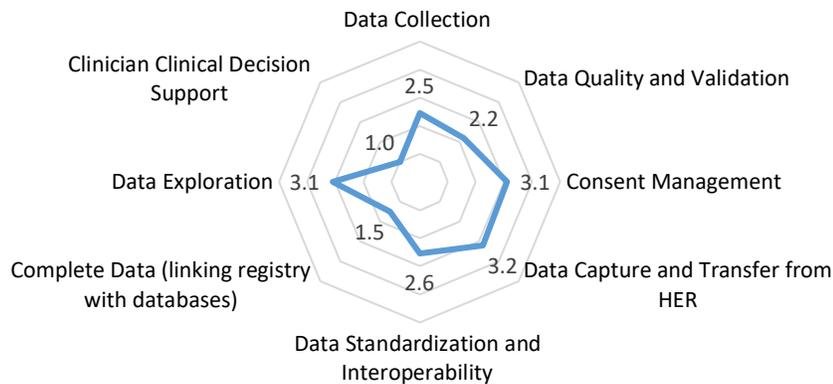


### ENGAGEMENT AND COMMUNITY BUILDING (2.8)

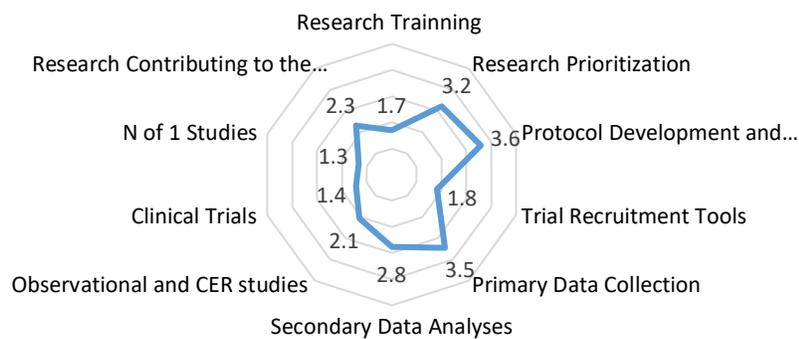


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### DATA AND ANALYTICS (2.5)



### RESEARCH (2.5)



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Table 2  
Highest to Lowest Individual Component Scores

	COMPONENT	SCORE
<b>Mature</b>	Common purpose	4.5
	Expectation that parents patients clinicians and researcher are co-creator	4.0
<b>Intermediate</b>	Membership policy	3.9
	Leadership system	3.7
	Protocol development and review	3.6
	Information from stakeholders	3.5
	Primary data collection	3.5
	Strategic planning for improvement of the network	3.3
	Communication to increase awareness of the network, opportunities for and	3.3
	IRB policies and procedures	3.3
	Network Policies and procedures for intellectual property	3.3
	Data capture and transfer from HER	3.2
	Research prioritization	3.2
	QI projects based on strategic plan	3.2
	Stakeholder participation in governance	3.1
	Feedback from patient community	3.1
	Consent management	3.1
	Data exploration	3.1
Managing improvement efforts	3.0	
<b>Beginning</b>	Network management	2.9
	QI learning by network participants shared with other practices	2.9
	Patient reported data	2.9
	Logistical support for research	2.9
	Understanding the organization as a system	2.9
	Secondary data analysis	2.8
	Family of measures	2.7
	Collaboration policy external to the network	2.6
	Data standardization and interoperability	2.6
	Accessibility to knowledge and tools and by network	2.5
	Financial sustainability	2.5
	Data collection	2.5
	Data transparency	2.3
	Network framework for improvement	2.3
	Research contributing to the science of improvement	2.3
	Data quality and validation	2.2
	Communication and publication of QI activities	2.2
	Methods for dissemination and spreads of key learning across care centers	2.2
	Facilitation stakeholder collaboration	2.2
Observational and CER studies	2.1	
<b>Not started</b>	QI education and training	1.8
	Development of leaders	1.7
	Competency in co-production and leadership	1.8
	Trial recruitment tools	1.8
	Research training	1.7
	Complete Data Linking with databases	1.5
	Clinical trials	1.4
	N of 1 studies	1.3
	Patient access to the registry of network database	1.3
	QI reports	1.3
	Clinician Clinical Decision Support	1.0

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### 3.1 *Systems of Leadership*

The CPRN 'Systems of Leadership' reflects the network's commitment to stakeholder involvement and multidisciplinary care and includes an executive committee consisting of two caregivers of children with CP, four physicians, two therapists, and two health services researchers. Several additional committees drive the activities of the network, including the community advisory, investigator, manuscript review, quality improvement and scientific review committees.

The mean 'Systems of Leadership' domain score was 3.2 (SD 0.5). Component scores ranged from a mature score of 4.5 (SD 0.5) for 'Common Purpose' to not started of 1.7 (SD 0.6) for 'Development of Leaders.' Mature status was achieved only for the component of 'common purpose', Intermediate status (score of 3 or above) was achieved for the components of 'leadership system', 'information from stakeholders', 'strategic planning for improvement of the network' and 'managing improvement efforts.' The components of 'Understanding the organization as a system', 'family of measures' and 'development of leaders' were rated below a score of 3 and areas for improvement.

### 3.2 *Governance and Management*

CPRN activities around 'Governance and Management' include established standard operating procedures (SOPs) to govern the network's development, organizational structure and membership, research, authorship processes and data sharing. Additional SOPs have been approved for formalizing mentorship, modifying the clinical registry, and developing a community registry. The clinical registry protocol has been developed, shared with network participants, and approved at 28 sites. A combination of a master reliance agreement with Nationwide Children's Hospital's Institutional Review

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Board governs six of these sites and the remainder have individual institutional approval for research.

Data sharing agreements have been signed with each institution and the Data Coordinating Center (DCC) is at the University of Utah.

The mean 'Governance and Management' domain score was 3.1 (SD 0.8). Component scores ranged from 3.9 for 'Membership Policy' to 2.5 for both 'Accessibility to Knowledge and Tools' and 'Financial Sustainability'. The components of 'Membership Policy', 'IRB policies and procedures', 'Network Policies and Procedures', 'Stakeholder Participation in governance', scored 3 (intermediate) or above, while 'Network management', 'Logistical support for research', 'Collaboration policy external to the network', 'financial sustainability', and 'Accessibility to knowledge and tools' scored below 3 and were areas for improvement.

Founded with a 10-year philanthropic gift, the network has not finalized its long-term financial sustainability. The initial financial support has been used to establish the DCC that consists of one FTE and several part-time employees and contractors to support the development and maintenance of its registry and its initial forays into research and quality improvement. The individual hospitals provide EHR support as part of clinical operations of the CP programs. CPRN does not directly support the salary of any of the network investigators, though three investigators thus far have received outside funding to support research activities using CPRN.

### *3.3. Quality Improvement*

Quality improvement is an essential part of the CPRN. The mean 'Quality Improvement' domain score was 2.4 (SD 0.6). Component scores ranged from 3.2 (SD 1.0) for 'QI projects Based on Strategic Plan' to 1.3 (SD 0.5) for 'QI reports'.

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Only one component, 'QI project based on strategic plan', scored a 3 intermediate or above. The remaining components of the Quality Improvement domain scored below 3 and were areas for improvement including 'QI learning by Network Participants shared with other practices', 'Network Framework for improvement', 'Data transparency', 'Communication and Publication of QI activities', 'Methods for Dissemination and Spreads of Key Learnings across care centers, 'QI education and training and', 'QI reports'.

CPRN developed its first QI project involving four centers initiated in 2017 reducing the intrathecal baclofen pump infection rate from 4.3 to 2.6 (Bollo 2019). Strategies learned from this are currently spreading to other network centers. Four CPRN leaders have formal training in quality improvement methodology with another leader scheduled to begin formal training winter 2021. Also beginning in 2020 a part time QI coach has been engaged enabling the network to begin work in three additional areas 1) screening for dystonia, 2) hip surveillance, and 3) adult outcomes across the network. These topics were chosen based on the strategic plan and feedback from the community.

#### *3.4 Engagement and Community Building*

At the core of the CPRN's mission, vision, and infrastructure is community engagement and community building. The mean 'Engagement and Community Building' domain score was 2.8 (SD 0.9). Component scores ranged from a mature score of 4 (SD 0.8) for 'Expectation that Parents, Patients Clinicians and Researchers are Co-creators' to Not started of 1.3 (SD 0.9) for 'Patient Access to the Registry or Network Database'. In addition to 'Expectation that parents, Patients clinicians and researchers are Co-Creators', two other components of this domain scored a 3 or above including 'Communication to Increase Awareness' and 'Feedback from Patient Community'. The components of 'Patient Reported Data', 'Facilitation Stakeholder Collaboration', 'Competency in Co-production and Leadership' and 'Patient Access to the registry' scored below 3 and were areas for improvement.

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The CPRN has initiated three large efforts to increase the awareness of the network and obtain feedback from the community. In 2017, an initiative to set a patient-centered research agenda for the network was funded in part through an engagement award from the Patient-Centered Outcomes Research Institute. Conducted in partnership with a leading patient advocacy organization (CP NOW), Research CP engaged a broad swath of the extended community – people with CP, parents and caregivers, advocates, clinicians and researchers – in a three-month long process to establish community driven priorities for research which are being used to drive the development of research and quality initiatives for the network. (Gross et al) Also in 2017, a Community Advisory Committee was established including 11 adults or adult caregivers and 12 parent caregivers. The Community Advisory Committee reviews network strategy and co-produces research and quality efforts on a volunteer basis. More recently in 2019, the MyCP Community Forum and Registry (<https://mycp.org/>) was established for members of the community to participate in research and discussions of research studies and priorities with investigators. With more than 1,000 members, MyCP provides community members regular opportunities to contribute to research through surveys that are posted in CPRN's Community Registry. An active private forum facilitates discussions among physician researchers and community members about their lived experience, published evidence for existing treatments and priorities in research.

### 3.5. Data and Analytics

A large effort of the CPRN to date has been to define common data elements (CDE's) for each discipline interacting with the person with CP, building these elements into electronic health records, deploying forms into clinical care, and transferring data to the data coordinating center. Reflecting these activities, the mean 'Data and Analytics' domain score was 2.5 (SD 0.7). Component scores ranged from 3.2 (SD 0.6) for 'Data Capture and Transfer from 'er' to 1 (SD 0) for 'Clinician Clinical decision support tools'.

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Intermediate status was achieved for components 'Data capture and transfer from Electronic record', and 'Data exploration and consent management'. The components of 'Data collection', 'Data quality and validation', 'Data standardization', 'Complete data linking registry with databases', and 'Clinician clinical decision support' scored below 3 intermediate and are areas for improvement.

To date, CDE's have been defined and are available at [www.cprn.org](http://www.cprn.org) with the intention of collecting them during clinical visits with Developmental Pediatricians, Physiatrists, Orthopedists, Neurosurgeons, and Physical Therapists. These have been deployed in eight centers that run the Epic EMR system (Epic Systems, Verona, WI) and seven non-Epic sites that are performing chart abstraction via REDCap (what company and where?). A recent baseline report (Gross 2020) included data from 1858 unique patients. Missing data ranges from 0-66%. Items with more than 14% missing data include: Manual Abilities Classification System Level (ref), Communication Function Classification System Level ,(ref) presence or absence of visual impairment, hearing impairment and constipation. Clinical sites are not required to enter all data fields on a patient to participate in the registry. Contributing to the missing data is the fact that the number of specialties serving individuals with CP and the variation in primary lead CP physician caring for children with CP varies at each center (for example at one center an orthopedist may lead care versus a developmental pediatrician, physical medicine and rehabilitation or neurology specialist at other centers ).

Chart abstraction processes and training for REDCap have also been developed to facilitate consistent data collection practices. The data transfer process is documented on the CPRN website including supplementary resources, program scripts and database queries so that sites can be self-sufficient in installing and deploying the registry. A similar set of EMR forms is being developed for the Cerner EMR and is anticipated for deployment in 2021. In addition to these resources, a registry

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explorer function is developing so that investigators can determine the quantity and quality of data for any given field in the clinical registry database.

#### 3.6. Research

The CPRN activities around the domain of research have included prioritization and creation of a research agenda<sup>(21)</sup> (Gross study), utilization of pilot data from the clinical registry to support funding applications and execution of both internally and externally funded studies. The mean 'Research' domain score was 2.5 (SD 0.4). Component scores ranged from 3.6 (SD 0.5) for 'Protocol Development and Review' to 1.3 (SD 0.5) for 'N of 1 studies'. Intermediate status was achieved for the components of 'Protocol development and review' and 'Primary data collection'. The components of 'Secondary Data', 'Research contributing to the science of improvement', 'Observational and CER studies', 'Trial recruitment tools', 'Research training', 'Clinical trials', and 'N of 1 s studies' scored below 3 and are areas for improvement.

Internally funded studies that have been completed include function and pain in adults<sup>(22, 23)</sup> (Gannotti 2020, Gannotti 2020) and practice variation for spasticity (Gross 2019).<sup>(24)</sup> Also underway and internally funded is the development of a research agenda specifically devoted to management of dystonia. Externally funded studies that are in progress include Genomic Insights into the neurobiology of CP (PI Kruer, National Institute of Neurological Disorders and Stroke), Enhancing a Multidisciplinary Research Network for Research and Quality in Epilepsy and CP (PI Ostendorf, Pediatric Epilepsy Research Foundation), Speech and Language Predictors of Participation for Children with CP (PI Allison, CP NOW) and Feasibility of Adding Grip Strength Measures to Body Composition Assessments in Individuals with CP (PI Hurvitz, Foundation for Physical Medicine and Rehabilitation).

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The CPRN executive committee leaders reviewed the component scores for each domain, identified and reached agreement on six areas of focus moving forward. These are Financial Sustainability, Development of Leaders, QI education, Data Quality and Validation, Primary Data Collection and Feedback from the Community.

### 4. Discussion

The purpose of this paper is to report on CPRN's progress toward developing as a LHN and provide detailed information about the strengths and opportunities for improvement. Our assessment indicates the CPRN LHN is strongest in the Domains of Systems of Leadership and Governance and Management with relative weaknesses in Quality improvement, Engagement and Community building, Data and Analytics, and Research. It is not surprising to us that scores in Systems of Leadership and Governance and Management were highest as these areas are foundational to initial startup before growth can occur in other domains of the network.

Scores on the individual components within domains revealed the network has reached a score of at least intermediate (3 or higher) in 19 components and below 3 in 31 components. Two components achieved a mature with score of 4 or higher in 'common purpose' and 'expectation that parent, patients, clinicians and researcher are co-creators.' None of the components achieved a score of 5 or idealized state. Our scores are similar to those of other young networks at about two years of age including All Children Thrive, the Autism Treatment Network, the Cystic Fibrosis Learning Network, and the Improving Renal Outcomes Collaborative which assessed their maturity of most domains below 3.(18) (Lannon 2020) CPRN maturity scores in this study seem appropriate for the length of time since CPRN's founding in 2015 and the beginning of data collection and assimilation. CPRN maturity scores in this

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study were lower than more mature networks such as Improve Care Now at age 10 years, which reported most domain scores at or above maturity with scores near 4.(18)

Review of the NMG scores with CPRN leaders identified 6 areas of focus moving forward. These are financial sustainability, development of leaders, QI education, Data quality and validation, primary data collection and feedback from the community. Similar to others that describe stable financial support as a barrier(17, 25) (Lannon 2013, Deans 2018) the CPRN network is exploring more stable funding sources. A five-year strategic planning process, initiated in 2020, set the priority to build an entity structure that would support multiple revenue streams including grants, participation fees, philanthropy, and sponsorship. With the exception of DCC staff, network participation in operations is voluntary. While external collaborations were initially dismissed to avoid any potential for undue influence or appearance of conflict, the network is considering establishing procedures for collaborating with industry. Greater financial support would allow us to increase the number of dedicated staff to the network. CPRN currently has less than four full-time staff whose time is committed to work of managing the network, while other more mature networks have up to 15; with a reported range of 2.6-15.5 depending on the age of the network.(18) (Lannon 2020) Although we have made progress we are not as advanced as we would have hoped at the five-year mark. Yet, we appreciate the time invested to develop the necessary infrastructure and the number of volunteer hours many of the members dedicated to building the network.

With regard to a focus on developing leaders, a recent paper describing the development of the LHS researcher provides excellent guidance. Forrest et al(26) describe core competencies (Forrest 2018) including systems science, standards of scientific evidence, research methods, informatics, ethics of research, implementation and improvement science, engagement, leadership and research management.

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There were several areas in the QI domain scoring below a 3 and the study team felt it was important to improve in all these areas. However, they agreed that improving QI education and training would lead to improvement in the other areas of the domain and agreed to start with a focus on this. Although the CPRN does have four leaders with QI education, the study team acknowledges there are opportunities to increase QI knowledge of working groups at each institution to strengthen and support the execution of improvement activities.

Like other studies(27) (Prospero 2019) the CPRN clinical registry reports missing or incomplete data. For this reason, the study team agreed that focusing on 'data quality and validation' in the next three to five years would be foundational to future growth in the Research domain, specifically in the ability to conduct observational and comparative effectiveness studies. Closely related to 'data quality and validation' is the component of 'primary data collection.' Improvements in primary data collection is an area the leaders felt could not be ignored and should be a focus in the coming years would have ripple effects towards improvement in other components of the network. Clinical sites are not required to enter on data fields on a patient in order to participate in the network. For example, care at one site may be delivered primarily by a developmental pediatrician while at another site orthopedists may take the lead role in care of individuals with CP. This is one reason there is not complete data on all patients in the registry from all clinical subspecialties and contributes to high rates of missing data.(28) (Gross 2020 methodology and baseline report) Efforts to increase the number of subspecialties submitting data on patients at each institution are needed.

Within the Engagement and Community Building Domain the study team agreed that focusing on 'patient reported data' should be a priority in the coming years. Patient reported data (2.9) which if collected routinely could be used by the system for management, research, and improvement. We have focused on collecting clinical data and anticipate improving the standardization of information collected

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during a clinic visit; simultaneously, CPRN is currently working on integrating several validated, CP-specific tools into the EHR.

The present study has limitations. Our sample of respondents was limited to 13 of 19 leaders that were invited to participate. Though these respondents represent a spectrum of disciplines and institutions. Similar to Lannon's report of nine networks assessing growth with the NMG, respondents in this study felt many components were interdependent and growth in one area is likely to lead to growth in another. Likewise, low scores in one component are likely to relate to low scores in another component. However, the study team felt the NMG was thorough in its assessment of several domains and components of domains which elucidated areas in need of greater focus and growth as well as identifying current relative strengths of the network. All respondents indicated this was helpful in providing an overview of the network's current status and areas important to develop further. All agreed that utilizing the tool to conduct regular self-assessments of the network would be beneficial moving forward. Results from this assessment will be utilized at strategic planning events to develop action plans and guide the network's growth in the identified areas.

### **5. Conclusion**

The CPRN has made substantial progress since beginning in 2015 towards becoming Learning Health network. Results from this project will provide the CPRN learning health network with a baseline for systems changes to prioritize areas for improvement and track improvement of the network over time.

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