

## **Pediatric Collaborative Networks for Quality Improvement and Research**

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## **Abstract**

Despite efforts of individual clinicians, pediatric practices, and institutions to remedy continuing deficiencies in pediatric safety and health care quality, multiple gaps and disparities exist. Most pediatric diseases are rare, thus few practices or centers care for sufficient numbers of children, particularly in subspecialties, to achieve large and representative sample sizes, and substantial between-site variation in care and outcomes persists.

Pediatric collaborative improvement networks are multi-site clinical networks that allow practice-based teams to learn from one another, test changes to improve quality, and use their collective experience and data to understand, implement, and spread what works in practice. The model was initially developed in 2002 by an American Board of Pediatrics Workgroup to accelerate the translation of evidence into practice, improve care and outcomes for children, and to serve as the gold standard for the performance in practice component of Maintenance of Certification requirements.

Many features of an improvement network derive from the Institute for Healthcare Improvement's collaborative improvement model Breakthrough Series™, including focus on a high-impact condition or topic; providing support from clinical content and quality improvement experts; using the Model for Improvement to set aims, use data for feedback and test changes iteratively; providing infrastructure support for data collection, analysis and reporting and quality improvement coaching; activities to enhance collaboration; and participation of multidisciplinary teams from multiple sites. In addition, they typically include a population registry of the children receiving care for the improvement topic of interest. These registries provide large and representative study samples with high quality data that can be used to generate information and evidence, as well as to inform clinical decision-making. In addition to quality improvement,

networks serve as large-scale health system laboratories providing the social, scientific and technical infrastructure and data for multiple types of research.

State-wide, regional and national pediatric collaborative networks have demonstrated improvements in primary care practice as well as care for chronic pediatric diseases (e.g., asthma, cystic fibrosis, inflammatory bowel disease, congenital heart disease), perinatal care, and patient safety (e.g., central line-associated blood stream infections, adverse medication events, surgical site infections); many have documented improved outcomes.

Challenges to spreading the improvement network model exist, including the need for the identification of stable funding sources. However, these barriers can be overcome, allowing the benefits of improved care and outcomes to spread to additional clinical and safety topics and care processes for the nation's children.

## **Collaborative Networks for Quality Improvement and Research in Pediatrics**

### **Introduction**

Despite efforts to improve care for children and families, multiple gaps and disparities in health care quality and outcomes for children exist.<sup>1,2,3,4</sup> Individual clinicians, pediatric practices, and institutions have undertaken a range of efforts in order to remedy continuing deficiencies in pediatric safety and quality. However, almost all pediatric diseases can be classified as ‘rare’ using the National Institutes of Health definition of a prevalence of fewer than 200,000 affected individuals in the U.S. Therefore, few individual practices or centers care for significant enough numbers of children, particularly in pediatric subspecialties, to achieve large and representative sample sizes, and substantial between-site variation in care and outcomes persists.

Pediatric collaborative improvement networks are multi-site clinical networks that allow practice-based teams to learn from one another, test changes to improve quality, and use their collective experience and data to understand and ultimately implement and spread what works in practice. In this manuscript, we build on recently summarized work<sup>5</sup> and describe the network model, provide examples of these networks in pediatrics, and discuss how pediatric collaborative networks can serve to close the quality gap and accelerate the translation of evidence into practice, resulting in improved care and outcomes for children. This work is primarily descriptive in nature and serves as an introduction to and review of the structure and utility of these networks; additional detail about their results achieved and impact on practice and research, can be found in the additional articles referenced.

### **History of the Pediatric Collaborative Improvement Network Model**

In 2002, the Quality in Pediatric Subspecialty Care workgroup, chartered by the American Board of Pediatrics (ABP), initially developed the model as a means to accelerate the translation of evidence into practice, improve care and outcomes for children, and to serve as the gold standard for the performance in practice component of Maintenance of Certification (MOC) requirements for subspecialty practice.<sup>6</sup> This model built on successful examples of cooperative multi-site clinical efforts that used data for learning and improvement such as the Children's Oncology Group,<sup>7</sup> the Northern New England Cardiovascular Disease Study Group,<sup>8,9,10</sup> and The Cystic Fibrosis Foundation.<sup>11</sup> Three pediatric collaborative improvement programs were subsequently launched with seed money from the American Board of Pediatrics Foundation (ImproveCareNow, the Children's Hospital Association Quality Transformation Network and the American Academy of Pediatrics' Chapter Quality Network). Currently, 9 of 14 pediatric subspecialties have implemented collaborative network improvement efforts (Table 1), engaging patients, families, clinicians, and researchers in working together to improve care and health outcomes. These pediatric networks serve as laboratories for innovation, and, for rare pediatric diseases, overcome sample size and statistical power concerns that limit the ability of single sites to improve and standardize care delivery.

Similar frameworks have now been endorsed by other national entities. The Institute of Medicine describes a Learning Healthcare System (LHS)<sup>12</sup> “in which knowledge generation is so embedded into the core of the practice of medicine that it is a natural outgrowth and product of the healthcare delivery process and leads to continual improvement in care”.<sup>13</sup> A LHS comprises patients and families, clinicians, and scientists who use data to learn from each clinical encounter in order to improve patient outcomes. This concept is also supported by the Patient Centered Outcomes Research Institute (PCORI) whose Methodology Committee recently

recommended using Rapid Learning Networks to improve outcomes and advance knowledge for patients, clinicians, and researchers.<sup>14</sup> Finally, multiple non-healthcare examples also provide support for the value of network collaboration for innovation and learning impact.<sup>15,16,17,18</sup> A prominent social scientist notes that networks are able to “see early, see more broadly, and translate information across groups”.<sup>19,20</sup>

### **How Pediatric Improvement Networks Work**

Many of the features of pediatric collaborative improvement networks are derived at least in part from the Breakthrough Series™ model, the Institute for Healthcare Improvement’s collaborative model for achieving improvement<sup>6</sup>:

- Focus on a high-impact condition, health topic or safety issue that can affect patient outcomes, engage caregivers, addresses a key population group, and is a widely recognized problem
- Support from both clinical content and quality improvement experts who provide evidence-informed ideas, guidance on appropriate methods, training on improvement science concepts/ principles, and ongoing coaching and support
- Use of the Model for Improvement<sup>21</sup> focusing on setting clear aims, measurable targets, using data for feedback, and testing changes quickly on a small scale to learn by doing
- Infrastructure support that includes monthly data collection, analysis and reporting; project management, and quality improvement coaching
- A series of defined collaborative activities (e.g., learning session workshops, monthly webinars, a listserv or other shared communication platform, and shared tools), and

- A critical mass of multidisciplinary teams from multiple sites involving front-line staff: physician engagement, nursing and administrative staff (and key others, as appropriate e.g., infection control, hospital quality leads, dieticians).

In addition, pediatric improvement networks typically create a population registry of the children receiving care for the improvement topic of interest. These registries, within and across network sites, provide large, diverse, and representative study samples with high quality data that can be used to generate information and evidence, as well as to inform clinical decision-making.

Initial funding is required to develop and initiate a collaborative improvement network's personnel and infrastructure. This design phase includes outlining key outcomes, metrics and implementation strategies.<sup>22,23,24</sup> Efforts are then focused on recruiting and engaging sites and teams, and the development and execution of human subjects approvals, data use agreements, and informed consent documents, followed by a pilot phase. As distinct from time-limited learning collaboratives, improvement networks begin with a plan to persist until aims are achieved and improvement is sustained. Therefore, continued investment in data infrastructure and site recruitment and support is required. Networks use a variety of funding mechanisms to support these ongoing operational costs, including participation fees, philanthropy, foundation grants, industry, state and federal contracts and awards.

### **Research in Collaborative Improvement Networks**

In addition to a key focus on quality improvement, networks provide a strong foundation for research which include: 1) a robust data infrastructure; 2) standardization of care processes to reduce practice-to-practice variation, thereby increasing the ability to detect the impact of changes, and 3) a mechanism to engage all the key stakeholders: patients, families, clinicians and

researchers in testing changes at the site of care delivery.<sup>25</sup> They serve as large scale health system laboratories that provide the social, scientific and technical infrastructure and data for multiple types of research including cohort, observational, and factorial design; comparative effectiveness studies; pragmatic trials; and dissemination and implementation evaluations. Most importantly, collaborative networks provide a structure and framework that enables the alignment of “the research agenda with questions that underlie patients and clinicians’ uncertainty about what works best at the front line for whom, under what circumstances.”<sup>26</sup>

## **Examples of Successful Networks for Improvement and Research**

### **Focus on patient safety**

#### Children’s Hospital Association Quality Transformation Network (QTN)

The Quality Transformation Network, managed by the Children's Hospital Association for its member hospitals, is the largest quality improvement network in pediatrics.<sup>27</sup> QTN conducts coordinated quality improvement collaboratives for high-impact pediatric topics. Initial efforts focused on preventing central line associated blood stream infections (CLABSIs) by standardizing practices related to line insertion and maintenance. In 29 PICUs participating in these collaboratives, the average aggregate CLABSI rate decreased 56% from 5.2 CLABSIs per 1000 line-days to 2.3 CLABSIs per 1000 line-days ( $p < .0001$ ) in the first three years.<sup>28</sup> By early September 2011, QTN had prevented an estimated 2,964 central line infections, saved 355 children’s lives, and provided estimated cost savings of \$103,722,423.<sup>29</sup> QTN has now extended its improvement efforts to pediatric hematology/oncology to reduce CLABSIs in children with *chronic* central lines both in inpatient and ambulatory settings, and to the reduction of peritoneal dialysis catheter infections in pediatric nephrology.



## Solutions for Patient Safety

Solutions for Patient Safety (SPS)<sup>30</sup> initially begin as a network of the 8 Ohio children's hospitals collaborating to improve outcomes in medication safety and surgical site infections. Between January of 2009 and December of 2010, the project resulted in a 60% reduction in surgical site infections in designated procedures and a 34.5% reduction in overall adverse drug events, saving an estimated 3,576 children from harm and over \$5.2mil in health care costs. This public-private partnership continues with a focus on reducing 8 types of harm by 50% by the end of 2015.

With funding from the Center for Medicare and Medicaid Services, the Solutions for Patient Safety network has expanded nationally to include 73 sites.

### **Improving perinatal care and outcomes**

The Vermont Oxford Network (VON) community of practice<sup>31</sup> includes a significant focus on improving clinical outcomes (e.g., nosocomial bacterial infection, lung damage) and family-centered care.<sup>32,33</sup> Several regional perinatal network efforts have launched in a number of states, building on their involvement in VON.<sup>34,35,36,37,38</sup> These include the California Perinatal Quality Care Collaborative (CPQCC)<sup>39</sup> and the Ohio Perinatal Quality Collaborative<sup>40</sup> (OPQC).

CPQCC has successfully tackled a number of important neonatal issues: reducing central-line associated bloodstream infections, increasing breastfeeding rates, and achieving normothermia by improving delivery room management. Initial OPQC improvement projects have resulted in: 1) a 20% sustained decrease in bloodstream infections in premature infants among 24 NICUs, and 2) 60% decrease in near term deliveries without medical indications (20 OB units), resulting in 6,000 fewer than expected Ohio births 36-38 weeks, and 180 fewer near-term infants admitted to the NICU *per year*.<sup>41,42,43,44,45,46</sup> The Pediatrix Medical Group has also successfully undertaken multiple perinatal improvement efforts across their nationwide network of neonatal

units.<sup>47</sup>

### **Disease-based networks**

#### The Cystic Fibrosis Foundation

The Cystic Fibrosis Foundation (CFF) mission is to assure the development of the means to cure and control Cystic Fibrosis and to improve the quality of life for those with the disease. The Foundation supports a national care network of clinical centers, including a registry that provides data for both quality improvement and research. In addition, 80 of these sites comprise the Therapeutic Development Network that conducts clinical trials to evaluate the safety and effectiveness of new CF therapies. The CFF posts individual center data on patient care and outcomes on its public Website.

#### ImproveCareNow

The ImproveCareNow Collaborative Chronic Care Network is a 50-site practice-based research and improvement network whose purpose is to transform the health, care, and costs for children and adolescents with Crohn's disease (CD) and ulcerative colitis (UC; together, inflammatory bowel disease). ImproveCareNow is building a sustainable collaborative chronic care network that enables patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery, and the application of new knowledge.

Participating clinicians have developed model care guidelines, tools, and processes to reduce variation<sup>48</sup> and ensure all patients receive optimal care.<sup>49,50</sup> An analysis of the first 6 centers participating in the network shows significant increases in the proportion of CD (from 55% to 68%) and UC (from 61% to 72%) patients with inactive disease. There was also a significant increase in the proportion of CD patients not taking prednisone (from 86% to 90%).<sup>51</sup> The increase in remission was achieved without the addition of new medications.

### National Pediatric Cardiology Quality Improvement Collaborative

The National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC) is a 46-site practice-based research and improvement network whose purpose is to improve dramatically the care and outcomes of children with cardiovascular disease. These current sites make up the majority of academic pediatric surgery centers in the U.S. that perform complex congenital heart surgery. The network convened in 2009 with 6 pilot sites with objectives to: 1) build a sustainable collaborative network of pediatric cardiologists, including a registry database, and collaborate on improvement and research projects; and 2) implement a quality improvement project to improve survival and quality of life of infants with hypoplastic left heart syndrome (HLHS) during the outpatient interstage period (i.e., between discharge from stage 1 Norwood and admission for Stage 2 bidirectional Glenn procedures).<sup>52,53, 54</sup> The risk of mortality and morbidity for infants with HLHS is amongst the highest for pediatric cardiology and cardiac surgery patients. Initial efforts by the network have improved care processes and identified a growth bundle associated with improved growth in these infants.<sup>55,56,57</sup>

### Pediatric Rheumatology Care and Outcomes Improvement Network

The Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN)<sup>58</sup> is an early-stage Learning Network focused on improving outcomes of children with juvenile idiopathic arthritis (JIA). Arthritis is the #1 cause of acquired disability in children and the 6th most common childhood disease. There is no cure for JIA, and the consequences of untreated or undertreated chronic arthritis can be significant. Established in June 2011, ten PR-COIN care sites are focused on improving care processes and outcomes to increase the number of children in JIA remission. Clinical teams and parents are jointly developing a shared decision-making tool to assist with discussion about the use of immune-modifying medications to decrease

disease activity.

### **State primary care improvement efforts**

The American Academy of Pediatrics (AAP) Chapter Quality Network (CQN) provides state chapters with support to lead quality improvement efforts at the primary care practice level, including a registry for asthma patients. The CQN is building a network of AAP chapters that has achieved measurable improvements in the health outcomes of children, particularly for those with asthma.<sup>59</sup>

The Vermont Child Health Improvement Program (VCHIP)<sup>60</sup> is a state population-based child and adolescent health services research and quality improvement program of the University of Vermont that is currently funded by state and federal matching funds. VCHIP provides leadership to the National Improvement Partnership Network (NIPN),<sup>61</sup> a network of over 15 states that have developed state or regional collaborations of public and private partners to advance quality and transform healthcare for children and their families. These partnerships usually involve the state chapter of the American Academy of Pediatrics and state agencies, e.g., the Department of Health and state Medicaid.

### **Conclusion**

Pediatric collaborative improvement networks apply scientific methods (including system science, quality improvement methodology, and qualitative research) and a structured approach to the design, development, and experimental testing of innovations in care delivery. They use collaboration and share data, ultimately standardizing practice. Therefore, variation in outcomes due to unreliable and unnecessary care delivery is reduced, increasing statistical power and allowing a stable system from which to test new strategies. Participation in improvement

networks fulfill Maintenance of Certification requirements for pediatricians, who are increasingly being held accountable for quality and clinical outcomes, resource utilization, appropriateness of recommended care, the responsibility to help improve systems of care, and for assuring care is patient-centered.<sup>62</sup> Most importantly, a number of networks are demonstrating significant improvements in child health and outcomes.

The American Board of Pediatrics has noted that “the use of collaborative networks is now a proven and transforming principle in pediatrics”.<sup>63,64</sup> Several factors appear important to the success of the collaborative model: focusing on outcomes, building community, effective use of technology, the application of scientific methods (including quality improvement), and the inclusion of patients and parents as co-creators and co-owners of the work.

Collaborative networks are especially important in pediatrics where, because of small numbers of patients in any health center, aggregation of data across multiple sites is necessary to understand and address child health problems. Networks focused on pediatrics are also valuable in identifying issues that may be specific to children’s health care. For example, the CLABSI data from QTN<sup>28,29</sup> and from OPQC,<sup>45,46</sup> emphasize the importance of the use of reliable maintenance bundle processes in reducing infections in pediatric intensive care settings. This was not noted to be a significant issue for adult CLABSI.

Challenges to spreading the improvement network model exist, including the need for more basic research to develop the evidence base for children’s healthcare, and identification of stable funding sources for developing new networks and providing ongoing support for existing ones. However, these barriers can be overcome, and a range of organizations are working to refine the start-up, implementation and sustainability of the network model in pediatrics, and to do it more effectively and efficiently. This will allow the benefits of improved care and health

outcomes to spread to additional clinical and safety topics and care processes in pediatrics. We must promote, implement and sustain collaborative networks that include both improvement and research to change the outcome for the nation's children and their families.

**Table 1: Pediatric Subspecialty Collaborative Improvement Networks**

<b>Pediatric Subspecialty</b>	<b>Pediatric Improvement Network</b>	<b>Quality Improvement Topic or Focus</b>
Cardiology	Joint Council on Congenital Heart Disease National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)	Hypoplastic left heart syndrome
Critical Care	Children’s Hospital Association Quality Transformation Network	Bloodstream infections in pediatric patients hospitalized in the ICU
Endocrinology	Cystic Fibrosis Foundation Care Center Network	Cystic fibrosis-related diabetes
Gastroenterology	ImproveCareNow	Inflammatory Bowel Disease
Hematology	Working to Improve Sickle Cell Healthcare (WISCH), National Initiative for Children’s Healthcare Quality	Sickle Cell Disease
Hematology/Oncology	Children’s Hospital Association Quality Transformation Network	Bloodstream infections in oncology patients with indwelling catheters
Neonatology	Vermont Oxford Network, Pediatrix, and multiple state networks	Premature infants
Nephrology	Children’s Hospital Association Quality Transformation Network	Infection in renal dialysis patients
Pulmonology	Cystic Fibrosis Foundation Care Center Network	Care and outcomes for children with cystic fibrosis
Rheumatology	Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN)	Juvenile idiopathic arthritis

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