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- Title of Project: PURSUING PERFECTION IN PEDIATRIC THERAPEUTICS
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- Organization: CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER
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Abstract:

Purpose: The pediatric Center for Education and Research in Therapeutics (CERT) at Cincinnati Children's Hospital (CCHMC) used Learning Networks (LNs) as unique laboratories for studying and improving the effectiveness of pediatric therapies. LNs are communities of patients, families, clinicians, and scientists that collaborate and use data to improve care and outcomes for children. The CERT aims were to:

- Enhance existing capabilities to develop and sustain large-scale health system laboratories capable of engaging front-line clinicians, researchers, patients, and parents in testing approaches to **translate research into practice, standardize care, and improve quality and safety.**
- Leverage the robust learning infrastructure to develop new knowledge, and **test and spread innovative strategies.**

Scope: We used CCHMC-supported LNs as the innovation engines and laboratories for CERT projects. The CCHMC CERT research group worked across multiple Learning Networks that, by August 2017, involved 558 teams at 286 institutions, 43 states, and five countries.

Methods: The LNs use quality improvement methods, practice-based registries, and implementation science to measure, study, and systematically improve the delivery and outcomes of care. The LNs served as the foundation for multiple research strategies, including shared decision making, observational studies, and dissemination and implementation studies. Co-production with patients and families accelerates innovation and improvement. The LNs developed and disseminated evidence-informed research in order to improve patient outcomes.

Results: The CERT supported multiple successful projects in several LNs, further developed the infrastructure to support LNs, and worked with multiple partners capable of disseminating research and education programs to a large majority of the nation's pediatric practitioners and tertiary care settings. The LNs achieve improved pediatric health outcomes.

Key Words: Child Health, Learning Networks, Pediatrics, Implementation Science, Quality, Safety

Purpose (Objectives of study):
As the only Center for Education and Research on Therapeutics (CERT) Research Center (RC) focused exclusively on children, Cincinnati Children's Hospital Medical Center (CCHMC) approved a series of projects unified by the theme of improving care and outcomes for children by optimizing the use of therapeutics. Subthemes were quality and safety.

The aims of the 2011-2016 grant were to:

- Enhance existing core capabilities to develop and sustain large-scale health system laboratories capable of engaging front-line clinicians, researchers, patients, and parents in testing approaches to **translate research into practice, standardize care, and improve quality and safety.**
- Leverage the robust learning infrastructure to develop new knowledge, and **test and spread innovative strategies.**

The Learning Networks Program of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center (CCHMC) received two awards from the AHRQ CERTs program, 2007-2011 and 2011-2016. The pediatric CERT at CCHMC, aligned with the Learning Networks Program, has always focused on improving child health through an emphasis on quality, safety, and learning networks.

Learning Networks are multisite organizations that improve the health of large populations of children and youth by enabling patients, families, clinicians, scientists, and health system leaders to collaborate, at scale, to accelerate improvement, discovery, and innovation. The Learning Network Program has operationalized the National Academy of Medicine's concept of the Learning Health System, in which clinical care, improvement, and research are integrated. They have produced a substantial impact on the health of children cared for at Cincinnati Children's, in Cincinnati, across Ohio, throughout the nation, and in the world.

Scope: We used CCHMC-supported LNs as the innovation engines and laboratories for CERT projects. The CCHMC CERT research group worked across multiple Learning Networks that, by August 2017, involved 558 teams at 286 institutions, 43 states, and five countries.

Methods: The LNs use quality improvement methods, practice-based registries, and implementation science to measure, study, and systematically improve the delivery and outcomes of care. The LNs served as the foundation for multiple research strategies, including shared decision making, observational studies, and dissemination and implementation studies. Co-production with patients and families accelerates innovation and improvement. The LNs developed and disseminated evidence-informed research in order to improve patient outcomes. The CERT was led by Core Faculty who worked as a multidisciplinary research team to design and oversee Learning Network efforts and research projects and offered scientific consultation and support to individual research project leaders.

Results: In 2007, CERT provided funding for six care centers in one network. The first two projects that the CCHMC pediatric CERT supported focused on pilot efforts regarding 1) safety at one children's hospital and 2) a multisite network for children with inflammatory bowel disease (IBD). **By 2016, CERT provided funding through the CCHMC Learning Networks Program to five networks and several developing networks that support 372 care centers at 249 organizations in 43 states, Canada, and the United Kingdom.** The five established learning networks, briefly described below, have all improved outcomes and developed new research knowledge. These include a regional perinatal network, a national children's hospital safety network, and three national chronic care networks.

Ohio Perinatal Quality Collaborative: Prior to 2008, reduction of early elective delivery (EED) had been accomplished in a few institutions or single health systems. **The Ohio Perinatal Quality Collaborative**

(OPQC) was the first state to reduce EED at the population level. With initial funding from CMMI 2008-2010, OPQC reduced early elective deliveries by 40% in the 20 largest maternity hospitals in Ohio; with additional funding from CMMI, CMS, CDC, and AHRQ, OPQC scaled this work to 105 (98%) of all maternity hospitals in the state and **reduced EED by 60% across the state**. **Between fall 2008 and 2017, as a result of OPQC EED efforts, more than 60,000 births in the state have shifted to term, saving more than $30 million dollars**. In addition, OPQC worked with Ohio Vital Statistics to improve accuracy and timeliness of the Ohio Birth Registry to make it a reliable instrument for EED and other perinatal quality improvement projects. OPQC has also improved infant outcomes by reducing bloodstream infections by 30% in infants hospitalized in the NICU and standardizing treatment in Ohio NICUs for the more than **8,000 infants with Neonatal Abstinence Syndrome between January 2014 and September 2017, resulting in reduced narcotic treatment and overall length of stay.** Also, **rates of birth <32 weeks gestation and <37 weeks gestation to mothers with a history of preterm birth have significantly decreased in participating OPQC hospitals, including to African American mothers and mothers on Medicaid**. Because these 20 maternity hospitals care for the majority of very preterm births, **rates for births <32 weeks gestation to mothers with a history of previous preterm birth, including for African American mothers and mothers on Medicaid, have decreased across all Ohio hospitals as well.**

Solutions for Patient Safety: In 2007, the CERT funded work on identifying Adverse Drug Events using trigger tool methodology at CCHMC. That evolved into a pilot improvement effort involving eight children's hospitals in Ohio. This effort received funding from the Cardinal Health Foundation and then from CMMI to expand into a national safety network. Partnering with the Children's Hospital Association, in 2016, **Solutions for Patient Safety (SPS) is a national, 88-site network of children's hospitals caring for 50% of all children hospitalized in the United States whose purpose is to eliminate serious harm across all children's hospitals**. **Between 2012 and June 2017, SPS efforts spared 9,093 children from serious harm and saved more than $148.5 million dollars in healthcare costs.** SPS has reduced falls by 81%, ventilator-associated pneumonias by 47%, adverse drug events by 42%, and surgical-site infections by 19%.

ImproveCareNow (ICN): ImproveCareNow, a network focused on pediatric inflammatory bowel disease (IBD), had six centers in its pilot network in 2007; in 2017, **ICN included 106 care centers and an estimated 60% of the children in the country with Crohn's disease and ulcerative colitis** and more than 33,000 children in its data registry. Remission rates have risen from 60% to 81%, which means that **more than 4,000 children are in remission today as a result of ICN's work**.

National Pediatric Cardiology Quality Improvement Collaborative In 2017, the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC) included 65 pediatric cardiology centers that care for children with complex congenital heart disease. This registry of infants is the largest in the world with >2,100 patients. **Since July 2013, the mortality rate across centers participating in NPCQIC has decreased by 43%; we estimate that this is approximately 50 lives saved *or the equivalent of two classrooms of kindergartners*.** NPCQIC has developed a bundle (or set of changes) that has improved growth outcomes in infants prior to their second open-heart surgery.

The Pediatric Rheumatology Care and Outcomes Improvement Network The Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) began in 2011 and is a growing network of 17 care centers focused on improving care and outcomes for children with juvenile idiopathic arthritis, a potentially crippling disease. By 2016, PR-COIN had **increased the portion of patients on medications in remission for at least 6 months from 37% to 44%; this represents 333 more children experiencing remission since November 2013**.

In 2016 and 2017, the **CCHMC Learning Networks Program** worked with additional organizations in designing collaborative efforts–the Autism Treatment Network, the Cystic Fibrosis Foundation, a six-state STORM network focused on sickle cell, the Improving Renal Outcomes Collaborative focused on pediatric kidney failure and renal transplant, and the Ohio Home Visiting Collaborative Learning Network.

Partnerships: The **Learning Networks Program** collaborates with the Children's Hospital Association, the American Board of Pediatrics, the American Academy of Pediatrics, the Ohio Department of Health, the Ohio Department of Medicaid, and the Ohio Government Resources Center. The CERT funding has leveraged an additional $50 million in awards from the Cardinal Health Foundation, the Children's Hospital Association, the Centers for Medicare and Medicaid Innovation, the Patient-Centered Outcomes Research Institute, the Centers for Disease Control and Prevention, state agencies in Ohio, and private foundations. As an example of partnership, in 2017, American Board of Pediatrics awarded the Learning Networks Program of the Anderson Center funding to co-produce a "Roadmap to Support the Resilience and Emotional Health of Children with Chronic Illness and their Families." This Roadmap Change Package is being co-produced with patients and parents from across multiple chronic disease Learning Networks.

Specific research projects: Below, we highlight selected projects from the Learning Networks funded by CERT:

1. Predict and prevent nephrotoxic medication-associated acute kidney injury in noncritically ill hospitalized children/Implementation of electronic health record surveillance to decrease nephrotoxic medication-associated AKI in hospitalized children (NINJA, Goldstein)
    - Developed and validated a predictive trigger tool for incipient AKI.
    - Implemented and evaluate da safety intervention to reduce AKI incidence, severity, and duration, and achieved a 33% decrease in AKI prevalence rate and a 40% decrease in high NTMx-exposure at CCHMC.
    - AKI work is being implemented in a subset of Solutions for Patient Safety hospitals.

2. Testing and Spread of Shared Decision-Making (SDM) Tools across Learning Networks (ICN and PR-COIN, Brinkman, Morgan)
    - Developed a variety of shared decision-making cards to assist families and clinicians in discussion considering medications for children with Juvenile Idiopathic Arthritis (JIA) with the Pediatric Rheumatology Care & Outcomes Improvement Network (PR-COIN). Achieved development of reliable care processes in care practices participating in the PR-COIN to 1) identify patients with JIA facing a decision to change or intensify medicine; 2) provide SDM support with our existing JIA medication "issue cards"; and 3) measure the outcomes that accrue process measures for SDM integrated into PR-COIN registry.
    - Designed and prototyped IBD Treatment Choice Cards (decision aid) through ICN working with five ICN sites based on known interest in SDM and capabilities with pre-visit planning.

3. Disseminated and implemented effective methods for using therapeutics to improve perinatal outcomes (OPQC, Kaplan)
    - Developed, tested, and widely disseminated an antenatal corticosteroids (ANCS) toolkit based on work in maternity hospitals participating in the Ohio Perinatal Quality Collaborative. ANCS toolkit: https://opqc.net/projects/OB-ANCS.
    - Successfully designed and implemented a stepped-wedge design to spread the OPQC 39-week project that has been completed in 70 maternity hospitals.

4. Situation Awareness to Reduce the Rate of UNSAFE Transfers and Serious Safety Events/Evaluating Huddle Effectiveness/Understanding How Huddles Improve Care (NPC-QIC and SPS, Brady, Walsh)

- 150 safety huddles at Cincinnati Children's Hospital were videotaped analyzed using the validated Communication and Teamwork Skills (CATS) assessment, with additions and adaptations reached through team consensus to code the high-risk "watcher" patient conversations. Huddles were debriefed with nurses and physicians
- Identified modifiable system and human factors associated with mitigation and escalation of risk and used the information to improve situation awareness.
- Ohio SPS collaborative found that the overall CATS score was associated with escalation in treatment and therapy within 2 hours after huddle, and the best predictors were briefing and requesting external resources.

5. Partnering with Parents to Support Decision Making About Hydroxyurea in Pediatric Sickle Cell Disease (STORM, Crosby, Walsh)
   - Worked with families to understand the needs of clinicians and parents of children with sickle cell disease (SCD) when faced with the decision to initiate hydroxyurea (HU).
   - Developed and tested a patient-centered multicomponent decision-support intervention (i.e., video narratives and a visit decision aid) to engage, inform, and prepare parents of children with SCD for involvement in the decision to initiate HU. On the basis of Dr. Crosby's CERT-funded research, in August 2017, from among a large pool of applicants, PCORI approved the application for funding, titled, "Engaging Parents of Children with Sickle Cell Anemia and their Providers in Shared Decision Making for Hydroxyurea."

6. Prospective observational study of digoxin in infants with single-ventricle congenital heart disease following stage-1 surgical palliation (NPC-QIC, Anderson)
   - Developed metrics for a network registry to monitor use of digoxin in a population of infants with complex congenital heart disease after documentation of association of reduced mortality in infants on digoxin during the interstage, and identified patient-level factors associated with digoxin treatment response.

By August 2017, the CCHMC Learning Networks Program has provided support for five networks and several developing networks that support 448 care centers at 286 organizations in 43 states, Belgium, Canada, Qatar, and the United Kingdom. During the no-cost extension of FY2017, the Learning Networks program developed its support infrastructure. Key components and progress are described in the table below:

Development of a Network Maturity Model	The Maturity Model is a "capability maturity matrix" commonly used in systems engineering to guide strategic planning using a framework for creating Learning Health Systems. The Model has six domains (governance, science, QI, technology, engagement, operations/management). The current version has undergone validation and testing with funding from PCORI. It is also being used by all current networks as a strategic planning tool to identify areas of opportunity for further development.
Data Dashboard	The Data Dashboard provides measures to support cross network learning. The primary measure is networks' progress toward meeting annual outcome goals. Other measures include Results - health outcomes, care process indicators (e.g., improvement goals attained); Reach - % of US clinicians participating, % of US population of patients touched; Research - # of projects and funding; data quality; Experience - network team experience, participation and contribution by teams to the network, engagement of patients and families, community building; and Revenue.
Learning Network Community Conferences	We engaged networks (five existing networks and four new networks) in two 1-day workshops each year for cross-network learning; attendance averaged 80-100 individuals. Community Conferences allow faculty and network staff to share successes and challenges as well as key data in a collaborative and learning environment. The Community Conferences provide a venue to facilitate cross network standardization of processes. The LN Program has also included a track for newer networks, to ensure that they are learning from each other as well as from more established networks.

Online Commons for Templates and How-to Manual	The online 'Commons' is a key component of the needed infrastructure to share tools and resources across networks and to facilitate real-time collaboration. Currently, the 'Commons' repository is a SharePoint site. Over 500 tools and resources have been contributed to date. We are developing a series of manuals of standards, aligned with the Network Maturity Model, that will provide guidance for the use of the tools, and we are currently piloting different approaches to drive increased utilization of the materials.
Cross-Network Program for Building Quality Improvement Capability	We offered two courses to build network teams' capability to effectively execute on QI activities: 1) an "Introduction to Quality Improvement" overview webinar (1 hour) to introduce teams to the Model for Improvement and the terminology of improvement science; and 2) a 6-month virtual "QI Fundamentals" course that involves webinars and project-based learning with expert feedback and coaching along the way as well as a cross-network learning. Participation has been strong: 73 clinicians, patients, and parents from across nine networks participated in the Intro to QI webinars; 48 teams from across nine networks have participated in one of the three 6-month QI Fundamentals courses offered.
Readiness Assessments for New Networks	To support potential new networks, the Program has developed standard communications materials and processes for engaging networks as well as a separate learning track at quarterly Community Conferences for prospective and emerging networks.
Introduction to Network Design (I2D) Workshops	The LN Program has developed, piloted, and now expanded a course designed to support the successful creation of new networks. This 1-day seminar provides information about key elements needed for the development of a successful learning network and provides follow-up support for action planning and proposal development as needed. To date, 38 participants representing 18 organizations have attended the I2D workshop; initial results from the I2D efforts include the successful submission of an LOI for oncofertility, the launch of a new cardiology network focused on heart failure, a proposed collaboration with Denmark and Sweden to utilize national quality registries for Learning Networks, and the connection of the Hydrocephalus Clinical Research Network with Solutions for Patient Safety. Following the initial workshops, we were approached to deliver this workshop to a national group of community-based networks, which took place in August 2017 with over 60 participants representing 22 different communities and initiatives.

Results Summary:

CERT program funding was instrumental in helping researchers achieve successful results in research projects in multiple Learning Networks. CERT funding also supported the development of a mature Learning Networks operational infrastructure. The Learning Networks Program at the James M. Anderson Center at Cincinnati Children's supported the development, design, and maturation of new and existing learning health networks. During the period of the grant, several new learning networks joined the existing five networks. All five veteran networks have achieved significant improvements in care and outcomes.

Publications and Project-Generated Resources from Selected CERTs Research Projects:

A Labor & Delivery Toolkit from the Ohio Perinatal Quality Collaborative: Optimizing Antenatal Use of Steroids to Improve Outcomes for Preterm Infants. (https://www.opqc.net/projects/OB-ANCS).

ANCS Presentation: Neonatal Abstinence Syndrome Project. Level 1 Webinar. Antenatal Corticosteroids Treatment. Ohio Perinatal Quality Collaborative. February 10 and February 19, 2015. Slides available at: https://opqc.net/sites/bmidrupalpopqc.chmcres.cchmc.org/files/Webinar%20Series/2015.02.19%20OPQC%20ANCS%20Webinar.pdf)

"Development of Tools to Facilitate Shared Decision Making About Medications for Juvenile Idiopathic Arthritis: A Project of the Pediatric Rheumatology Care and Outcomes Improvement Network" for presentation in a poster session at the 2013 ACR/ARHP Annual Meeting, to be held in San Diego, CA, October 25-30. *****Also chosen by the ACR Communications and Marketing Committee to be highlighted to the media during the ACR Annual Meeting in San Diego.

Lipstein E, Brinkman W, Sage J, et al. Understanding treatment decision making in juvenile idiopathic arthritis: a qualitative assessment. *Pediatric Rheumatology Online Journal*. 2013 Sep 30;11(1):34. PMID: 24079577.

Goldstein, S, Kirkendall, E, Nguyen, H, et al. Electronic Health Record Identification of Nephrotoxin Exposure and Associated Acute Kidney Injury. *Pediatrics*. 2013; Volume 132, Issue 3. DOI: 10.1542/peds.2013-0794. PMID: 23940245.

Crosby, L, Shook, L, Ware, R, et al. Shared decision making for hydroxyurea treatment initiation in children with sickle cell anemia. *Pediatric Blood & Cancer*. DOI 10.1002/pbc. 2014. PMID: 25308571.

Crosby, L, Britto, M, Kalinyak, K, et al. Hydroxyurea decision making process for parents of children with sickle cell disease [Abstract]. *Journal of Sickle Cell Disease and Hemoglobinopathies*. 1(1), 31. DOI 10.14223. 2014.

Kaplan, H, Sherman, S, Cleveland, C, et al. Reliable implementation of evidence: a qualitative study of antenatal corticosteroid administration in Ohio hospitals. *BMJ Quality and Safety*. http://dx.doi.org/10.1136/bmjqs-2015-003984. 2015. PMID: 26056321.

Anderson, J, Beekman R, Kugler, J. Improvement in Interstage Survival in a National Pediatric Cardiology Learning Network. *Circulation. Cardiovascular quality and outcomes*. 8.10.1161/CIRCOUTCOMES.115.001956. 2015. PMID: 26058717.

Brady P, Zix J, Brilli R, Wheeler D, et al. Developing and evaluating the success of a family activated medical emergency team: a quality improvement report. *BMJ Quality & Safety.* 2015; 24(3); 203-11. PMID: 25516987.

Brown D, Mangeot C, Anderson J, et al. Digoxin Use Is Associated With Reduced Interstage Mortality in Patients With No History of Arrhythmia After Stage I Palliation for Single Ventricle Heart Disease. *Journal of the American Heart Association*. 2016;5(1). 2016. PMID: 26755552.

Brinkman W, Lipstein E, Taylor J, et al. Design and implementation of a decision aid for juvenile idiopathic arthritis medication choices. Pediatric Rheumatology Online Journal. 2017;15(1):48. 2017. PMID: 28583183.

APPENDIX A: Learning Networks Publications (2011-2017):

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Improvement/outcomes	Crandall W, Kappelman MD, Colletti RB, et al	ImproveCareNow: The development of a pediatric inflammatory bowel disease improvement network	Inflammatory bowel diseases	2011;17(1):450-457	20602466	2011	ICN
Improvement/outcomes	Crandall WV, Boyle BM, Colletti RB, Margolis PA, Kappelman MD	Development of process and outcome measures for improvement: lessons learned in a quality improvement collaborative for pediatric inflammatory bowel disease	Inflammatory bowel diseases	2011;17(10):2184-2191	21456033	2011	ICN
Methods	Kappelman MD, Crandall WV, Colletti RB, et al	Short pediatric Crohn's disease activity index for quality improvement and observational research	Inflammatory bowel diseases	2011;17(1):112-117	20812330	2011	ICN
Improvement/outcomes	Anderson JB, Iyer SB, Beekman RH, III, et al	National pediatric cardiology quality improvement collaborative: Lessons from development and early years	Progress in pediatric cardiology	2011;32(2):103-109		2011	NPC-QIC
Epidemiology	Iyer SB, Anderson JB, Slicker J, Beekman RH, III, Lannon C	Using statistical process control to identify early growth failure among infants with hypoplastic left heart syndrome	World journal for pediatric & congenital heart surgery	2011;2(4):576-585		2011	NPC-QIC

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Epidemiology	Lee GJ, Kappelman MD, Boyle B, et al	Role of sex in the treatment and clinical outcomes of pediatric patients with inflammatory bowel disease	Journal of pediatric gastroenterology and nutrition	2012;55(6):701-706	22744192	2012	ICN
Improvement/outcomes	Crandall WV, Margolis PA, Kappelman MD, et al	Improved outcomes in a quality improvement collaborative for pediatric inflammatory bowel disease	Pediatrics	2012;129(4):e1030-1041	22412030	2012	ICN
Epidemiology	Anderson JB, Iyer SB, Schidlow DN, et al	Variation in growth of infants with a single ventricle	The journal of pediatrics	2012;161(1):16-21	22336578	2012	NPC-QIC
Science of LN	Lannon CM, Peterson LE	Pediatric collaborative networks for quality improvement and research	Academic pediatrics	2013;13(6 Suppl):S69-74	24268088	2013	NPC-QIC
Science of LN	Donovan EF, Sparling K, Lake MR, et al	The investment case for preventing NICU-associated infections	American journal of perinatology	2013;30(3):179-184	22836823	2013	OPQC
Hypothesis testing	Ghelani SJ, Spurney CF, Martin GR, Cross RR	Impact of pharmacotherapy on interstage mortality and weight gain in children with single ventricle	Congenital heart disease	2013;8(3):219-227	23157489	2013	NPC-QIC
Methods	Slicker J, Hehir DA, Horsley M, et al	Nutrition algorithms for infants with hypoplastic left heart syndrome: birth through the first interstage period	Congenital heart disease	2013;8(2):89-102	22891735	2013	NPC-QIC

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Methods	Brennan CW, Groves PS, Colletti RB	Implementation of a registry for quality improvement	Implementation science	2013;8(1):S4		2013	ICN
Epidemiology	Menon SC, McCandless RT, Mack GK, et al	Clinical outcomes and resource use for infants with hypoplastic left heart syndrome during bidirectional Glenn: summary from the Joint Council for Congenital Heart Disease National Pediatric Cardiology Quality Improvement Collaborative registry	Pediatric cardiology	2013;34(1):143-148	22673966	2013	NPC-QIC
Methods	Lipstein EA, Brinkman WB, Sage J, Lannon CM, Morgan Dewitt E	Understanding treatment decision making in juvenile idiopathic arthritis: a qualitative assessment	Pediatric rheumatology online journal	2013;11(1):34	24079577	2013	PR-COIN
Improvement/outcomes	Billett AL, Colletti RB, Mandel KE, et al	Exemplar pediatric collaborative improvement networks: achieving results	Pediatrics	2013;131 Suppl 4:S196-203	23729760	2013	ICN
Science of LN	Clancy CM, Margolis PA, Miller M	Collaborative networks for both improvement and research	Pediatrics	2013;131 Suppl 4:S210-214	23729762	2013	LN Program
Science of LN	Lannon CM, Peterson LE	Pediatric collaborative improvement networks: background and overview	Pediatrics	2013;131 Suppl 4:S189-195	23729759	2013	LN Program
Hypothesis testing	Markham KB, Iams J	Universal or selective cervical length screening?	Contemporary OB/GYN	2013		2013	OPQC

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Epidemiology	Cross RR, Harahsheh AS, McCarter R, Martin GR	Identified mortality risk factors associated with presentation, initial hospitalisation, and interstage period for the Norwood operation in a multi-centre registry: a report from the national pediatric cardiology-quality improvement collaborative	Cardiology in the young	2014;24(2):253-262	23388401	2014	NPC-QIC
Science of LN	Anderson JB, Beekman RH, III, Kugler JD, et al	Use of a learning network to improve variation in interstage weight gain after the Norwood operation	Congenital heart disease	2014;9(6):512-520	25358553	2014	NPC-QIC
Science of LN	Forrest CB, Margolis P, Seid M, Colletti RB	PEDSnet: how a prototype pediatric learning health system is being expanded into a national network	Health affairs	2014;33(7):1171-1177	25006143	2014	ICN
Methods	Park KT, Crandall WV, Fridge J, et al	Implementable strategies and exploratory considerations to reduce costs associated with anti-TNF therapy in inflammatory bowel disease	Inflammatory bowel diseases	2014;20(5):946-951	24451222	2014	ICN
Science of LN	Seid M, Margolis PA, Opipari-Arrigan L	Engagement, peer production, and the learning healthcare system	JAMA pediatrics	2014;168(3):201-202	24446048	2014	ICN

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Epidemiology	Adler J, Dong S, Eder SJ, Dombkowski KJ	Perianal Crohn Disease in a Large Multicenter Pediatric Collaborative	Journal of pediatric gastroenterology and nutrition	2017;64(5):e117-e124		2014	ICN
Improvement/outcomes	Hoffenberg EJ, Park KT, Dykes DM, et al	Appropriateness of emergency department use in pediatric inflammatory bowel disease: a quality improvement opportunity	Journal of pediatric gastroenterology and nutrition	2014;59(3):324-326	24918980	2014	ICN
Epidemiology	Lee GJ, Dotson JL, Kappelman MD, et al	Seasonality and Pediatric Inflammatory Bowel Disease	Journal of pediatric gastroenterology and nutrition	2014;59(1):25-28	24614123	2014	ICN
Epidemiology	Baker-Smith CM, Wilhelm CM, Neish SR, et al	Predictors of prolonged length of intensive care unit stay after stage I palliation: a report from the National Pediatric Cardiology Quality Improvement Collaborative	Pediatric cardiology	2014;35(3):431-440	24104215	2014	NPC-QIC
Improvement/outcomes	Toltzis P, O'Riordan M, Cunningham DJ, et al	A Statewide Collaborative to Reduce Pediatric Surgical Site Infections	Pediatrics	2014;134(4):e1174-e1180	25201794	2014	SPS
Hypothesis testing	Forrest CB, Crandall WV, Bailey LC, et al	Effectiveness of anti-TNFalpha for Crohn disease: research in a pediatric learning health system	Pediatrics	2014;134(1):37-44	24935993	2014	ICN

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Epidemiology	Hill GD, Hehir DA, Bartz PJ, et al	Effect of feeding modality on interstage growth after stage I palliation: a report from the National Pediatric Cardiology Quality Improvement Collaborative	The journal of thoracic and cardiovascular surgery	2014;148(4):1534-1539	24607373	2014	NPC-QIC
Hypothesis testing	Boyle BM, Kappelman MD, Colletti RB, Baldassano RN, Milov DE, Crandall WV	Routine use of thiopurines in maintaining remission in pediatric Crohn's disease	World journal of gastroenterology: WJG	2014;20(27):9185-9190	25083093	2014	ICN
Methods	Iams JD	Identification of candidates for progesterone: why, who, how, and when?	Obstetrics and gynecology	2014;123(6):1317-1326	24807317	2014	OPQC
Epidemiology	Oster ME, Ehrlich A, King E, et al	Association of Interstage Home Monitoring With Mortality, Readmissions, and Weight Gain: A Multicenter Study from the National Pediatric Cardiology Quality Improvement Collaborative	Circulation	2015;132(6):502-508	26260497	2015	NPC-QIC
Improvement/outcomes	Anderson JB, Beekman RH, III, Kugler JD, et al	Improvement in Interstage Survival in a National Pediatric Cardiology Learning Network	Circulation cardiovascular quality and outcomes	2015;8(4):428-436		2015	NPC-QIC

Category	Author(s)	Article Title	Journal	Citation	PMID	Year	Network
Improvement/outcomes	Lihn SL, Kugler JD, Peterson LE, Lannon CM, Pickles D, Beekman RH, III	Transparency in a Pediatric Quality Improvement Collaborative: A Passionate Journey by NPC-QIC Clinicians and Parents	Congenital heart disease	2015;10(6):572-580	26554878	2015	NPC-QIC
Science of LN	Clauss SB, Anderson JB, Lannon C, et al	Quality improvement through collaboration: the National Pediatric Quality improvement Collaborative initiative	Current opinion in pediatrics	2015;27(5):555-562	26208236	2015	NPC-QIC
Methods	Marsolo K, Margolis PA, Forrest CB, Colletti RB, Hutton JJ	A Digital Architecture for a Network-Based Learning Health System: Integrating Chronic Care Management, Quality Improvement, and Research	EGEMS (Washington, DC)	2015;3(1):1168	26357665	2015	ICN
Improvement/outcomes	Kaplan HC, Mangeot C, Sherman SN, et al	Dissemination of a quality improvement intervention to reduce early term elective deliveries and improve birth registry accuracy at scale in Ohio	Implementation science	2015;10(1):A2		2015	OPQC
Methods	Dotson JL, Crandall WV, Zhang P, et al	Feasibility and validity of the pediatric ulcerative colitis activity index in routine clinical practice	Journal of pediatric gastroenterology and nutrition	2015;60(2):200-204	25221935	2015	ICN
Methods	Tung J, Grunow JE, Jacobs N	Pilot Development of an Electronic Pediatric Inflammatory Bowel Disease Quiz Game	Journal of pediatric gastroenterology and nutrition	2015;61(3):292-296	25793902	2015	ICN

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Epidemiology	Baker-Smith CM, Goldberg SW, Rosenthal GL	Predictors of Prolonged Hospital Length of Stay Following Stage II Palliation of Hypoplastic Left Heart Syndrome (and Variants): Analysis of the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) Database	Pediatric cardiology	2015;36(8):1630-1641	26036350	2015	NPC-QIC
Epidemiology	Brown DW, Cohen KE, O'Brien P, et al	Impact of prenatal diagnosis in survivors of initial palliation of single ventricle heart disease: analysis of the National Pediatric Cardiology Quality Improvement Collaborative database	Pediatric cardiology	2015;36(2):314-321	25135602	2015	NPC-QIC
Epidemiology	Schidlow DN, Gauvreau K, Patel M, Uzark K, Brown DW	Site of interstage care, resource utilization, and interstage mortality: a report from the NPC-QIC registry	Pediatric cardiology	2015;36(1):126-131	25107545	2015	NPC-QIC
Improvement/outcomes	Schaffzin JK, Harte L, Marquette S, et al	Surgical Site Infection Reduction by the Solutions for Patient Safety Hospital Engagement Network	Pediatrics	2015;136(5):e1353-1360	26438709	2015	SPS
	Bailit JL, Lappen JR	Stillbirth and the 39-Week Rule: Can We Be Reassured?	Obstetrics and gynecology	2015;126(6):1131-1132	26551189	2015	OPQC

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Methods	Kaplan HC, Sherman SN, Cleveland C, Goldenhar LM, Lannon CM, Bailit JL	Reliable implementation of evidence: a qualitative study of antenatal corticosteroid administration in Ohio hospitals	BMJ quality & safety	2016;25(3):173-181	26056321	2016	OPQC
Improvement/outcomes	Dykes D, Williams E, Margolis P, et al	Improving pediatric Inflammatory Bowel Disease (IBD) follow-up	BMJ quality improvement reports	2016;5(1)	27559472	2016	ICN
Improvement/outcomes	Savarino JR, Kaplan JL, Winter HS, Moran CJ, Israel EJ	Improving Clinical Remission Rates in Pediatric Inflammatory Bowel Disease with Previsit Planning	BMJ quality improvement reports	2016;5(1)	27559471	2016	ICN
Epidemiology	Slicker J, Sables-Baus S, Lambert LM, Peterson LE, Woodard FK, Ocampo EC	Perioperative Feeding Approaches in Single Ventricle Infants: A Survey of 46 Centers	Congenital heart disease	2016;11(6):707-715	27410425	2016	NPC-QIC
Improvement/outcomes	Lyren A, Brilli R, Bird M, Lashutka N, Muething S	Ohio Children's Hospitals' Solutions for Patient Safety: A Framework for Pediatric Patient Safety Improvement	Journal for healthcare quality	2016;38(4):213-222	26042749	2016	SPS
Hypothesis testing	Brown DW, Mangeot C, Anderson JB, et al	Digoxin Use Is Associated With Reduced Interstage Mortality in Patients With No History of Arrhythmia After Stage I Palliation for Single Ventricle Heart Disease	Journal of the American Heart Association	2016;5(1)		2016	NPC-QIC

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Epidemiology	Hill GD, Rudd NA, Ghanayem NS, Hehir DA, Bartz PJ	Center Variability in Timing of Stage 2 Palliation and Association with Interstage Mortality: A Report from the National Pediatric Cardiology Quality Improvement Collaborative	Pediatric cardiology	2016;37(8):1516-1524	27558553	2016	NPC-QIC
Improvement/outcomes	Fisher M	Moving the Needle in Children's Health with National Collaborative Networks—A CEO's Perspective	Pediatric quality & safety	2016;1(1):e002		2016	LN Program
Epidemiology	Singer AA, Gadepalli SK, Eder SJ, Adler J	Fistulizing Crohn's Disease Presenting After Surgery on a Perianal Lesion	Pediatrics	2016;137(3):e20152878	26908665	2016	ICN
Epidemiology	Hanke SP, Joy B, Riddle E, et al	Risk Factors for Unanticipated Readmissions During the Interstage: A Report From the National Pediatric Cardiology Quality Improvement Collaborative	Seminars in thoracic and cardiovascular surgery	2016;28(4):803-814	28417868	2016	NPC-QIC
Science of LN	Batalden M, Batalden P, Margolis P, et al	Coproduction of healthcare service	BMJ quality & safety	2016;25(7):509-517	26376674	2017	ICN
Methods	Wernovsky G, Lihn SL, Olen MM	Creating a lesion-specific "roadmap" for ambulatory care following surgery for complex congenital cardiac disease	Cardiology in the young	2017;27(4):648-662	27373527	2017	NPC-QIC

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Science of LN	Ramsey LB, Mizuno T, Vinks AA, Margolis PA	Learning Health Systems as Facilitators of Precision Medicine	Clinical pharmacology and therapeutics	2017;101(3):359-367	27984650	2017	ICN
Epidemiology	Carlo WF, Cnota JF, Dabal RJ, Anderson JB	Practice trends over time in the care of infants with hypoplastic left heart syndrome: A report from the National Pediatric Cardiology Quality Improvement Collaborative	Congenital heart disease	2017;12(3):315-321	28121380	2017	NPC-QIC
Methods	Turner D, Carle A, Steiner SJ, et al	Quality Items Required for Running a Paediatric Inflammatory Bowel Disease Centre: An ECCO Paper	ECCO-JCC	2017:1-7	28789473	2017	ICN
Epidemiology	Lengyel CS, Ehrlich S, Iams JD, Muglia LJ, DeFranco EA	Effect of Modifiable Risk Factors on Preterm Birth: A Population-Based Cohort	Maternal and child health journal	2017;21(4):777-785	27485494	2017	OPQC
Epidemiology	Fernandez RP, Joy BF, Allen R, et al	Interstage Survival for Patients with Hypoplastic Left Heart Syndrome After ECMO	Pediatric cardiology	2017;38(1):50-55	27803957	2017	NPC-QIC
Improvement/outcomes	Frank G, Walsh KE, Wooton S, et al	Impact of a Pressure Injury Prevention Bundle in the Solutions for Patient Safety Network	Pediatric quality & safety	2017;2(2):e013		2017	SPS

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Methods	Brinkman WB, Lipstein EA, Taylor J, et al	Design and implementation of a decision aid for juvenile idiopathic arthritis medication choices	Pediatric rheumatology online journal	2017;15(1):48	28583183	2017	PR-COIN
Epidemiology	Burch PT, Ravishankar C, Newburger JW, et al	Assessment of Growth 6 Years after the Norwood Procedure	The journal of pediatrics	2017;180:270-274	27855999	2017	NPC-QIC