

# Collaborative Networks for Both Improvement and Research

## abstract

Moving significant therapeutic discoveries beyond early biomedical translation or T1 science and into practice involves: (1) T2 science, identifying “the right treatment for the right patient in the right way at the right time” (eg, patient-centered outcomes research) and tools to implement this knowledge (eg, guidelines, registries); and (2) T3 studies addressing how to achieve health care delivery change. Collaborative improvement networks can serve as large-scale, health system laboratories to engage clinicians, researchers, patients, and parents in testing approaches to translate research into practice. Improvement networks are of particular importance for pediatric T2 and T3 research, as evidence to establish safety and efficacy of therapeutic interventions in children is often lacking. Networks for improvement and research are also consistent with the Institute of Medicine’s Learning Healthcare Systems model in which learning networks provide a system for improving care and outcomes and generate new knowledge in near real-time. Creation of total population registries in collaborative network sites provides large, representative study samples with high-quality data that can be used to generate evidence and to inform clinical decision-making. Networks use collaboration, data, and quality-improvement methods to standardize practice. Therefore, variation in outcomes due to unreliable and unnecessary care delivery is reduced, increasing statistical power, and allowing a consistent baseline from which to test new strategies. In addition, collaborative networks for improvement and research offer the opportunity to not only make improvements but also to study improvements to determine which interventions and combination of strategies work best in what settings. *Pediatrics* 2013;131:S210–S214

**AUTHORS:** Carolyn M. Clancy, MD,<sup>a</sup> Peter A. Margolis, MD, PhD,<sup>b</sup> and Marlene Miller, MD, MSc<sup>c,d</sup>

<sup>a</sup>Agency for Healthcare Research and Quality, Rockville, Maryland; <sup>b</sup>Cincinnati Children’s Hospital Medical Center, Cincinnati, Ohio; <sup>c</sup>Children’s Hospital Association, Alexandria, Virginia; and <sup>d</sup>Johns Hopkins Children’s Center, Baltimore, Maryland

### KEY WORDS

Learning Networks, Rapid Learning Networks, Learning Healthcare System, quality improvement

### ABBREVIATIONS

QI—quality improvement

QTN—Quality Transformation Network

The content is solely the responsibility of the authors and does not necessarily represent the official view of the Agency for Healthcare Research and Quality.

[www.pediatrics.org/cgi/doi/10.1542/peds.2012-3786H](http://www.pediatrics.org/cgi/doi/10.1542/peds.2012-3786H)

doi:10.1542/peds.2012-3786H

Accepted for publication Feb 27, 2013

Address correspondence to Carolyn M. Clancy, MD, Director, AHRQ, John M. Eisenberg Building, 540 Gaither Rd, Rockville, MD 20850. E-mail: carolyn.clancy@ahrq.hhs.gov

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2013 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

**FUNDING:** The conference on which the articles in this supplement were based was funded by the American Board of Pediatrics Foundation, the National Association of Children’s Hospitals and Related Institutions (now the Children’s Hospital Association), the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center, and the pediatric Center for Education and Research on Therapeutics, supported by cooperative agreement number U19HS021114 from the Agency for Healthcare Research and Quality.

Collaborative improvement networks use quality improvement (QI) methods to translate evidence into practice and support teams to test and implement strategies that will change outcomes in a highly reliable way. In addition, these networks provide a strong foundation for research by developing a robust data infrastructure and standardizing care processes that lead to a stable baseline for experimentation. Networks also provide a mechanism to engage all the key stakeholders: patients, families, clinicians, and researchers. In this article, we describe how collaborative improvement networks can serve as powerful laboratories for discovery and new knowledge.

Substantial public and private investment in basic science and translation into clinical research, described as translation at the first level or T1 science,<sup>1</sup> has resulted in significant therapeutic discoveries with the potential to achieve major improvements in health outcomes. The challenge remains to move these advances rapidly into practice. Moving beyond early biomedical translation involves T2 science (identifying “the right treatment for the right patient in the right way at the right time” [eg, patient-centered outcomes research] and the creation of tools that are needed to implement this knowledge [eg, guidelines, registries]) as well as T3 studies that address how to achieve health care delivery change, including measurement and accountability, implementation and system redesign, scaling and spread, and a feedback loop as the lessons learned at the frontlines from clinicians and patients lead to new questions.

The Institute of Medicine has promoted the concept of Learning Healthcare Systems “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 health care

delivery process and leads to continual improvement in care.”<sup>2,3</sup> Despite this compelling vision, few if any examples of such systems exist. We believe that networks specifically designed for improvement and research are consistent with the Institute of Medicine model. These are rapid learning networks that provide a system for improving care and outcomes and generating new knowledge in near real-time.<sup>4</sup> Collaborative networks used for both improvement and research enable the careful linkage of research to generate discovery and new knowledge with the ongoing use of QI methods to ensure that evidence is employed in practice to change outcomes in a highly consistent way.

### THE PARTICULAR IMPORTANCE OF NETWORKS FOR PEDIATRIC RESEARCH

Children, especially those with chronic illness, stand to benefit greatly from collaborative improvement networks that provide opportunities for T2 and T3 translational patient-centered outcomes research. Most drugs, biologic agents, and medical devices marketed to adults are investigated by using randomized controlled trials. However, these modalities are less commonly tested in children for a variety of reasons. For the most part, pediatric chronic conditions are rare, and the number of clinicians available to provide care is small. In addition, research studies involving children encounter regulatory and consent concerns that can make them unappealing to implement. Furthermore, few centers care for significant enough numbers of children to achieve large and representative sample sizes, and substantial variation exists in care delivery across centers. Thus, basic evidence to establish safety and efficacy of therapeutic interventions in children (let alone their effectiveness in real-world settings) is often lacking.<sup>5,6</sup>

The evidence-grading exercise used during identification of the initial

recommended core set of children’s health care quality measures for the Children’s Health Insurance Program Reauthorization Act provides compelling confirmation of the need for more evidence of clinical effectiveness of services for children.<sup>7</sup> Only 2 of 24 initial core measures from this act were able to be given the highest evidence grade of A. Thirteen measures in the core set received grades of B, and several measures received D grades, the lowest grade.<sup>8</sup>

Collaboration, data sharing, and a focus on populations across many clinical sites have long been a model in research to generate new knowledge. Collaborative improvement networks can provide the robust clinical data infrastructure needed to support a variety of research purposes and designs. Creation of total population registries within and across network sites provides large, diverse, and representative study samples with high-quality data. Registry data can be used to generate information and evidence, as well as to inform clinical decision-making. Networks use collaboration, data, and QI methods to standardize practice. Therefore, variation in outcomes due to unreliable and unnecessary care delivery is reduced, increasing statistical power and allowing a consistent baseline from which to test new strategies. Increasing sample sizes through networks is also a feasible strategy for addressing known barriers to publishing pediatric QI research.<sup>9</sup> The ability of networks to combine multisite collaboration and a population data infrastructure will enable studies of the effectiveness of pediatric care and outcomes.

### THE VALUE OF ENGAGING MULTIPLE STAKEHOLDERS: EXAMPLES OF NETWORK RESEARCH

An essential strength of collaborative improvement networks is that they are

composed of multiple stakeholders: patients and families, clinicians, and researchers who use data to learn from each clinical encounter to improve patient outcomes. Although each stakeholder group brings a different strength and perspective, all are aligned on the goal of improving care and results for children and families.

### Patients and Families

Networks, particularly those focusing on chronic conditions, provide an infrastructure that can facilitate patient and family involvement. Engaged patients and families, in turn, can help to identify areas for further exploration, provide feedback on what is working for them, and work collaboratively with clinicians and researchers to design and test improved tools and systems. Parents in care centers participating in the National Pediatric Cardiology Quality Improvement Collaborative<sup>10</sup> and in ImproveCareNow<sup>11</sup> are serving as members of their centers' improvement teams, as well as providing resources for other parents and developing outreach via social media platforms. As a part of the Collaborative Chronic Care Network Project, patients with inflammatory bowel disease are participating in N-of-1 trials, experiments designed jointly by a patient and a clinician to determine how the individual patient responds to specific treatments or interventions.<sup>12</sup> Patients and family in the Children's Hospital Association Quality Transformation Network (QTN) are direct partners, receiving education and, for example, needing to do best care practice hands-on demonstrations of the bundles to reduce infections in chronic central lines and peritoneal dialysis catheters. If an infection should occur, the patient and family caregivers go through a targeted retraining and retesting process with the goal of preventing additional infections. Families also learn to monitor how their child's central line is cared for in other settings,

such as community emergency departments and outpatient clinics. In addition, the nascent Pediatric Rheumatology Care and Outcomes Innovation Network<sup>13</sup> is working with patients, families, clinicians, and researchers to develop a shared decision-making tool about the use of powerful medications in children with juvenile idiopathic arthritis.

### Clinicians

Networks must engage front-line clinical teams. These connections provide a strong foundation for testing what works in practice, and they enable the development of new knowledge. By linking research to care delivery and engaging clinicians directly, networks provide a forum for user-led, participatory research. Not only are the clinician users of comparative effectiveness research in a unique position to identify critical health care knowledge gaps, they along with their patients are the final common pathways for change. For example, 1 of the sites participating in the Ohio Perinatal Quality Collaborative, concerned about discrepancies between team-collected and state-mandated birth certificate data, developed a QI effort to foster collaboration between clinical and data abstractors to enhance the accuracy of the birth certificate<sup>14</sup>; this work is now being disseminated in Ohio as part of a national pilot effort funded by the Centers for Disease Control and Prevention.<sup>15</sup> Front-line providers in the Children's Hospital Association QTN identified the need to critically evaluate ancillary products (ie, chlorhexidine-impregnated sponges) to prevent central line-associated bloodstream infections, which spurred innovative assessment efforts.

### Researchers

Networks engage researchers by providing access and involving not only those who use the system (patients) but also those who comprise the system

(patients, clinicians, and staff). In this way, networks are able to address real-world questions efficiently and effectively by linking researchers with patients, families, and frontline clinicians. This connection is evidenced by several research efforts about comparative benefits and harms and important patient outcomes in pediatric collaborative improvement networks. For example, using data from their registry (2700 patients), the ImproveCare-Now Network is currently pursuing the largest comparative effectiveness study to date for pediatric patients with Crohn's disease, with a special focus on advancing therapeutic knowledge on the optimal timing of introducing biologic agents into a patient's treatment regimen.<sup>16</sup> Researchers in the Children's Hospital Association QTN used a nonrandomized factorial study within a longitudinal interrupted time series design across 29 PICUs to evaluate the use of specific bundle components to prevent central line-associated bloodstream infections.<sup>17</sup> These researchers, armed with >1 million central line days in their data, are exploring key associations between central line infections and patient and provider characteristics. Comparably, pediatric hematology/oncology researchers in the Children's Hospital Association QTN have assembled the largest collection of patient-specific data on ambulatory central line infections and are exploring associations between ambulatory care (from both providers and families) and central line infections. Finally, the National Pediatric Cardiology Quality Improvement Collaborative used data from its network registry to identify factors related to growth in infants with complex congenital heart disease; a bundle of these components is now being used as part of the network's improvement efforts.<sup>18</sup>

The ability to identify key findings and rapidly disseminate them to clinical

teams and patients can be a useful output of collaborative improvement networks. Involving multiple stakeholders changes the research paradigm, replacing the traditional model (which places the researcher at the center of the process) with 1 that involves engaged patients and families and clinical teams, finding ways to work together with researchers to understand and address patient needs.<sup>19</sup> Learning becomes a partnership enterprise among the patients, clinicians, and researchers, using the patient interaction at the point of care as the knowledge engine.

### USING NETWORKS TO STUDY IMPROVEMENT METHODS

Collaborative networks for improvement and research offer the opportunity to not only make improvements but also to study improvements. Although a range of interventions have shown promise in reducing gaps between evidence and practice,<sup>20–22</sup> many unanswered questions remain about how to rapidly spread successful change strategies.<sup>23,24</sup> Evidence suggests that audit and feedback, academic detailing, and QI methods can all be effective means to improve practice in care.<sup>21,26–27</sup> Networks provide

the base to determine which interventions and which combination of strategies work best in what settings. In addition, networks might be useful in determining whether and which aspects of local context are barriers or facilitators to successful implementation.<sup>28</sup> Finally, the large number of sites involved in a network provide an opportunity to assess and compare the effectiveness of strategies for dissemination, scale, and spread.

Conventional health services research has tended to focus on describing problems in care delivery rather than fixing them. The dynamic, changing nature of systems, the need for participation and cooperation by frontline providers, and the role of organizational and other contextual factors in determining the success of interventions are examples of significant technical challenges to undertaking such studies. Ensuring the effective use of evidence requires knowledge about what treatments work, as well as knowledge about how to make sure that knowledge is applied in practice. QI and implementation research involves the design, development, and evaluation of interventions aimed at the redesign of the health care system to produce

improved outcomes.<sup>29</sup> Although applied widely in other industries, the use of systems improvement methods with their emphasis on actively planned and often multifactor experimentation to learn in complex systems has not been broadly adopted to study health care delivery and outcomes.

### CONCLUSIONS

Pediatric collaborative improvement networks can serve as large-scale, health system laboratories, capable of engaging frontline clinicians, researchers, patients, and parents in testing approaches to translate research into practice, standardize care, and improve quality and safety. Such networks provide the infrastructure and database for multiple types of research: cohort, observational, and factorial design; comparative effectiveness studies; pragmatic trials; and dissemination and implementation evaluations, among others. Most importantly, collaborative networks provide a structure and framework that enable the alignment of “the research agenda with questions that underlie patients and clinicians’ uncertainty about what works best for whom, under what circumstances.”<sup>30</sup>

### REFERENCES

1. Dougherty D, Conway PH. The “3T’s” road map to transform US health care: the “how” of high-quality care. *JAMA*. 2008;299(19):2319–2321
2. Olsen LA, Aisner D, McGinnis JM, eds. The Learning Healthcare System: Workshop Summary (*Institute of Medicine Roundtable on Evidence-Based Medicine*). Washington, DC: The National Academies Press; 2007
3. Institute of Medicine. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington, DC: The National Academies Press; September 2012
4. McCannon CJ, Perla RJ. Learning networks for sustainable, large-scale improvement. *Jt Comm J Qual Patient Saf*. 2009;35(5):286–291
5. Simpson LA, Peterson L, Lannon CM, et al. Special challenges in comparative effectiveness research on children’s and adolescents’ health. *Health Aff (Millwood)*. 2010;29(10):1849–1856
6. Cohen E, Uleryk E, Jasuja M, Parkin PC. An absence of pediatric randomized controlled trials in general medical journals, 1985–2004. *J Clin Epidemiol*. 2007;60(2):118–123
7. Dougherty D, Clancy C. Transforming children’s health care quality and outcomes—a not-so-random non-linear walk across the translational continuum. *Acad Pediatr*. 2011;11(suppl 3):S91–S94
8. Grades of Recommendation, Oxford Centre for Evidence Based Medicine. Available at: [www.cebm.net/index.aspx?o=1047](http://www.cebm.net/index.aspx?o=1047). Accessed April 16, 2012
9. Van Cleave J, Dougherty D, Perrin JM. Strategies for addressing barriers to publishing pediatric quality improvement research. *Pediatrics*. 2011;128(3). Available at: [www.pediatrics.org/cgi/content/full/128/3/e678](http://www.pediatrics.org/cgi/content/full/128/3/e678)
10. National Pediatric Cardiology Quality Improvement Collaborative. For parents by parents. Available at: <http://jccchdq.org/parents>. Accessed July 27, 2012

11. Families: ImproveCareNow. Available at: <https://improvecarenow.org/families>. Accessed July 27, 2012
12. Collaborative Chronic Care Network. N of 1 trials. Available at: <http://c3nproject.org/innovations/n-1-trials>. Accessed July 27, 2012
13. Pediatric Rheumatology Care and Outcomes Innovation Network (PR-COIN). Available at: <http://pr-coin.org/>. Accessed July 27, 2012
14. Kamath BD, Donovan EF, Christopher R, Brodbeck J, Slone C, Marcotte MP. Using improvement science to increase accuracy and reliability of gestational age documentation. *Am J Perinatol*. 2012;29(3):217–224
15. Centers for Disease Control and Prevention. Cooperative Agreement Number 5U38DP003787-02
16. Building Modular Chronic Disease Registries for QI and Comparative Effectiveness Research. Available at: <https://improvecarenow.org/news/enhanced-registries-grant>. Accessed July 17, 2012
17. Miller MR, Niedner MF, Huskins WC, et al; National Association of Children's Hospitals and Related Institutions Pediatric Intensive Care Unit Central Line-Associated Bloodstream Infection Quality Transformation Teams. Reducing PICU central line-associated bloodstream infections: 3-year results. *Pediatrics*. 2011;128(5). Available at: [www.pediatrics.org/cgi/content/full/128/5/e1077](http://www.pediatrics.org/cgi/content/full/128/5/e1077)
18. Anderson JB, Iyer SB, Schidlow DN, et al; National Pediatric Cardiology Quality Improvement Collaborative. Variation in growth of infants with a single ventricle. *J Pediatr*. 2012;161(1):16–21, e1, quiz 21, e2–e3
19. Patient-Centered Outcomes Research Institute. Funding announcement: improving healthcare systems. Available at: [www.pcori.org/assets/PFA-Improving-Healthcare-Systems-05222012.pdf](http://www.pcori.org/assets/PFA-Improving-Healthcare-Systems-05222012.pdf). Accessed February 26, 2012
20. Althabe F, Buekens P, Bergel E, et al; Guidelines Trial Group. A behavioral intervention to improve obstetrical care. *N Engl J Med*. 2008;358(18):1929–1940
21. Chaillet N, Dubé E, Dugas M, et al. Evidence-based strategies for implementing guidelines in obstetrics: a systematic review. *Obstet Gynecol*. 2006;108(5):1234–1245
22. Donovan EF, Lannon C, Bailit J, et al; Ohio Perinatal Quality Collaborative Writing Committee. A statewide initiative to reduce inappropriate scheduled births at 36(0/7)-38(6/7) weeks' gestation [published correction in *Am J Obstet Gynecol*. 2010;202(6):603]. *Am J Obstet Gynecol*. 2010;202(3):243. e1–8
23. Institute of Medicine. *Advancing Quality Improvement Research: Challenges and Opportunities, Workshop Summary*. Washington, DC: The National Academies Press; 2007
24. Institute of Medicine. *The State of Quality Improvement and Implementation Research: Expert Views, Workshop Summary*. Washington, DC: The National Academies Press; 2007
25. Davis D, O'Brien MA, Freemantle N, Wolf FM, Mazmanian P, Taylor-Vaisey A. Impact of formal continuing medical education: do conferences, workshops, rounds, and other traditional continuing education activities change physician behavior or health care outcomes? *JAMA*. 1999;282(9):867–874
26. Davis DA, Thomson MA, Oxman AD, Haynes RB. Changing physician performance. A systematic review of the effect of continuing medical education strategies. *JAMA*. 1995;274(9):700–705
27. Mazmanian PE, Davis DA. Continuing medical education and the physician as a learner: guide to the evidence. *JAMA*. 2002;288(9):1057–1060
28. Kaplan HC, Provost LP, Froehle CM, Margolis PA. The Model for Understanding Success in Quality (MUSIQ): building a theory of context in healthcare quality improvement. *BMJ Qual Saf*. 2012;21(1):13–20
29. Margolis P, Provost LP, Schoettker PJ, Britto MT. Quality improvement, clinical research, and quality improvement research—opportunities for integration. *Pediatr Clin North Am*. 2009;56(4):831–841
30. Patient-Centered Outcomes Research Institute. Draft methodology report: "Our questions, our decisions: Standards for patient-centered outcomes research". PCORI Methodology Committee. Helfand M, Berg A, Flum D, Gabriel S, Normand S-L, eds. Published for Public Comment July 23, 2012

## Collaborative Networks for Both Improvement and Research

Carolyn M. Clancy, Peter A. Margolis and Marlene Miller

*Pediatrics* 2013;131;S210

DOI: 10.1542/peds.2012-3786H

### Updated Information & Services

including high resolution figures, can be found at:  
[http://pediatrics.aappublications.org/content/131/Supplement\\_4/S210](http://pediatrics.aappublications.org/content/131/Supplement_4/S210)

### References

This article cites 16 articles, 4 of which you can access for free at:  
[http://pediatrics.aappublications.org/content/131/Supplement\\_4/S210#BIBL](http://pediatrics.aappublications.org/content/131/Supplement_4/S210#BIBL)

### Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):  
**Administration/Practice Management**  
[http://www.aappublications.org/cgi/collection/administration:practice\\_management\\_sub](http://www.aappublications.org/cgi/collection/administration:practice_management_sub)  
**Quality Improvement**  
[http://www.aappublications.org/cgi/collection/quality\\_improvement\\_sub](http://www.aappublications.org/cgi/collection/quality_improvement_sub)

### Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:  
<http://www.aappublications.org/site/misc/Permissions.xhtml>

### Reprints

Information about ordering reprints can be found online:  
<http://www.aappublications.org/site/misc/reprints.xhtml>

# American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Collaborative Networks for Both Improvement and Research**

Carolyn M. Clancy, Peter A. Margolis and Marlene Miller

*Pediatrics* 2013;131;S210

DOI: 10.1542/peds.2012-3786H

The online version of this article, along with updated information and services, is located on the World Wide Web at:

[http://pediatrics.aappublications.org/content/131/Supplement\\_4/S210](http://pediatrics.aappublications.org/content/131/Supplement_4/S210)

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2013 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

## American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

