

# ImproveCareNow: The Development of a Pediatric Inflammatory Bowel Disease Improvement Network

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**Background:** There is significant variation in diagnostic testing and treatment for inflammatory bowel disease. Quality improvement science methods can help address unwarranted variations in care and outcomes.

**Methods:** The ImproveCareNow Network was established under the sponsorship of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition and the American Board

of Pediatrics as a prototype for a model of improving subspecialty care that included three components: 1) creating enduring multi-center collaborative networks of pediatric subspecialists, 2) sharing of performance data collected in patient registries, and 3) training in quality improvement. The network began with a focus on improving initial diagnostic testing and evaluation, the classification of the severity and extent of disease, the detection and treatment of inadequate nutrition and growth, and the appropriate dosing of immunomodulator medications. Changes are based on an evidence-based model of chronic illness care involving the use of patient registries for population management, previsit planning, decision support, promoting self-management, and auditing of care processes.

**Results:** Currently, patients are being enrolled at 23 sites. Through 2009, data have been analyzed on over 2500 patients from over 7500 visits. Initial results suggest improvements in both care processes (e.g., appropriate medication dosing and completion of a classification bundle that includes the patient's diagnosis, disease activity, distribution and phenotype, growth status, and nutrition status) and outcomes (e.g., the percentage of patients in remission).

**Conclusions:** These improvements suggest that practice sites are learning how to apply quality improvement methods to improve the care of patients.

(*Inflamm Bowel Dis* 2011;17:450–457)

**Key Words:** inflammatory bowel disease, quality improvement, collaboration, chronic illness

Received for publication April 30, 2010; Accepted May 19, 2010.

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Funded by the participating sites and a grant from the Centers for Education and Research in Therapeutics of the US Agency for Health Care Quality and Research; Grant Number: U18HS016957.

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DOI 10.1002/ibd.21394

Published online 2 July 2010 in Wiley Online Library (wileyonlinelibrary.com).

Chronic diseases are the leading causes of death and disability in the United States.<sup>1</sup> Approximately 133 million Americans live with at least one chronic illness and as many as 1.4 million suffer from inflammatory bowel disease (IBD).<sup>1–4</sup> IBD is estimated to account for more than 700,000 physician visits and 100,000 hospitalizations each year and results in disability for ≈119,000 patients.<sup>2,5</sup> IBD is also associated with substantial economic burden. A recent analysis of nearly 20,000 patients determined that

the mean annual costs were over \$8,000 for patients with Crohn's disease (CD) and over \$5,000 for patients with ulcerative colitis (UC).<sup>6</sup> Hospitalizations, outpatient care, and pharmaceutical claims were each responsible for roughly one-third of costs in both groups.

There is growing national attention on the urgent need to improve the quality of healthcare.<sup>7,8</sup> Large gaps exist between recommended care and actual clinical practice. Adults receive only 50%–60% of recommended acute, chronic, and preventive healthcare<sup>9,10</sup> and children receive only 42% of recommended care.<sup>11</sup> Data from smaller studies of patients with IBD are consistent with these findings of significant variations in care. In an examination of 65 adult patients with confirmed IBD, Reddy et al<sup>12</sup> found that there was suboptimal dosing of maintenance medications, prolonged use of corticosteroids, failure to use steroid-sparing agents, and inadequate attention to metabolic bone disease and screening for colorectal cancer. Colletti et al<sup>13</sup> found similar results in a study of 246 pediatric patients with CD. They noted variation in diagnostic interventions, including stool tests for pathogens, imaging of the small intestine, measurement of thiopurine methyltransferase before starting treatment with a thiopurine, and testing for tuberculosis before starting treatment with infliximab. In addition, treatments were often not started at doses recommended for initial treatment and many severely underweight patients did not receive nutritional interventions. As noted recently by Kappelman et al,<sup>14</sup> “there is a clear need for translating evidence-based practices into the actual practice and follow-up provided for patients.” Pressure to improve quality and reduce costs has accelerated efforts to reform healthcare advances.<sup>15</sup>

We report here the design and development of an approach to overcome these gaps in the quality of care for children with IBD.

## HISTORY OF IMPROVECARENOW

In the past, specialty certification has emphasized assessment of individual knowledge rather than actual performance in practice. Extensive evidence has demonstrated that traditional continuing education has limited effects on physicians' performance in practice.<sup>16–18</sup> The American Board of Medical Specialties (ABMS) recognized that a broad range of skills, abilities, and professional behaviors were essential to the continued delivery of safe and effective patient care. The Member Boards of ABMS voted in 2000 to create the ABMS Maintenance of Certification (MOC) program, a more continuous process of recertification in which physicians are required to document their performance in practice.<sup>19</sup> As this program evolves, the majority of American physicians will be required to participate in ongoing ABMS Member Board MOC programs to document competency in patient care, systems-based thinking, and practice-

based learning and improvement, in addition to medical knowledge, communication skills, and professional behavior.

The ImproveCareNow Network was established as the prototype for a model created by the American Board of Pediatrics (ABP) called Quality in Subspecialty Care (QPSC) that would be extended to all 13 pediatric subspecialties.<sup>20</sup> This model included three components: 1) creating enduring multicenter collaborative networks of pediatric subspecialists, 2) sharing of performance data collected in patient registries, and 3) training in quality improvement methods.

ImproveCareNow has its roots in PIBDNet—the Pediatric IBD Network for Research and Improvement—that was awarded a 2-year grant from the ABP in cooperation with the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) in 2004. Guided by the vision of the ABP to facilitate practice-based improvement activities that would enable pediatric gastroenterologists to meet new competency requirements in systems thinking and performance in practice resulting in improved outcomes for patients, PIBDNet undertook two projects. The first was the design of a network focused on IBD quality improvement. We used a structured methodology for new product design to guide the design process.<sup>21</sup> The initial design process anticipated four stages, as shown in Figure 1: 1) planning and setting aims, 2) developing testable ideas and measures, 3) testing the collaborative improvement program as a prototype, and 4) detailed design, spread and scale-up to other subspecialties.

The second project was a cohort study to evaluate variation in care in pediatric CD. With the participation of 93 pediatric gastroenterologists at 48 practice sites, the study was completed in 2008 and the findings published in 2009.<sup>13</sup>

At the end of the 2-year grant, the cohort study had been undertaken and the design completed for the improvement network. The components of the network are described below.

## NETWORK DESIGN COMPONENTS

The design and development of the ImproveCareNow Network brings together three major components to support large-scale improvement across multiple care centers at once: 1) instruction and ongoing coaching in quality improvement methods, 2) application of the evidence-based Chronic Illness Care model as a framework for improving care, and 3) use of an adapted Breakthrough Series (BTS) method to support the development of an enduring collaborative improvement network.

### Quality Improvement

Quality improvement science methods can help address unwarranted variations in care and outcomes and produce sustainable changes in systems of care delivery. Developed by W. Edwards Deming, the science of quality

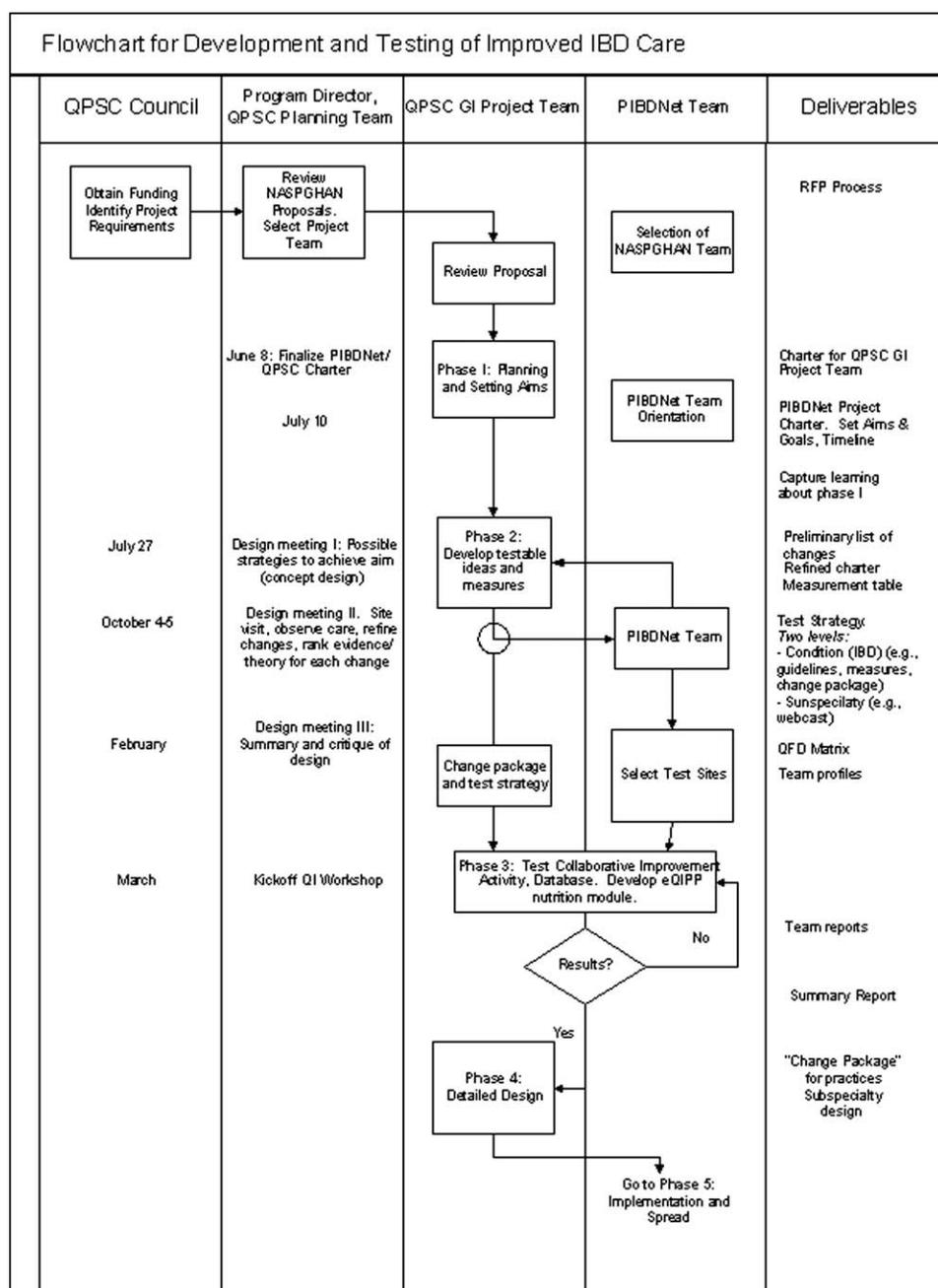


FIGURE 1. Flowchart for the development and testing of ImproveCareNow.

improvement focuses on four basic components: understanding how the diverse components of a system interact, understanding variation (e.g., random or common cause versus nonrandom or special cause variation), the psychology of change (understanding what motivates people to change), and the theory of knowledge.<sup>22</sup> The theory of knowledge emphasizes the use of formal, structured application of the scientific method to learn in complex systems. The Model for Improvement<sup>23</sup> provides a practical framework, based on Deming's approach, for testing, revising,

and extending hypotheses for improving a system (Fig. 2). The model has four key elements: aim, measurement, ideas for change, and tests of change. The first three elements are exemplified by three key questions: 1) What are we trying to accomplish? 2) How will we know that a change is an improvement? 3) What changes can we make that will result in an improvement? The final element is a disciplined approach to rapid testing and learning from change called the Plan-Do-Study-Act (PDSA) cycle (Fig. 3). Using the model, large improvement projects can be broken down into

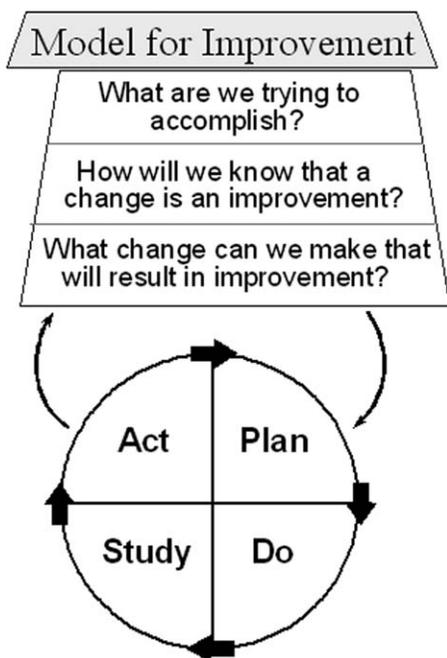


FIGURE 2. The model for improvement. Reprinted with permission from Langley G, Nolan K, Nolan T, et al. *The Improvement Guide. A Practical Approach to Enhancing Organizational Performance*. San Francisco: Jossey-Bass; 1996. Reprinted with permission of John Wiley & Sons, Inc.

manageable pieces and addressed through a series of small-scale PDSA cycles. Use of quality improvement science methods has been successful in a wide variety of settings, including the care of patients with chronic illness, primary care, hospital care, and public health.<sup>24-26</sup> A major emphasis is on sustainability by providing care providers with the skills and tools required to continue changes over time.

**Improving the Chronic Illness Care Model**

Developed more than a decade ago, the Chronic Care Model is a widely adopted, integrated framework to guide the development of health care delivery to provide patient-centered and evidence-based care to improve outcomes for patients with chronic illness.<sup>27-31</sup> The goal of the Chronic Care Model is to enable more productive interactions between informed and activated patients and a prepared and proactive healthcare team. The model identifies six areas that are determinants of improved systems for chronic illness care: linkages to community resources, self-management support, decision support, delivery system design, clinical information systems, and organization of the health system. A review of the studies published since 2000 suggests that redesigning care using the Chronic Care Model generally leads to improvements in the quality of care and outcomes for patients with chronic illnesses, although there is often a delay in seeing improvements in clinical outcomes.<sup>32</sup>

**Collaborative Learning Network**

Pediatric CD and UC, like many other pediatric chronic conditions, meet the National Institutes of Health (NIH) definition for a rare disease.<sup>33</sup> No single care center has a sufficient number of patients to produce generalizable knowledge, a barrier that, unless addressed by networks, will slow the pace of knowledge acquisition and outcomes improvement. The ImproveCareNow network was designed to emulate other pediatric clinical networks that use data for research and (increasingly) improvement. Examples include the Vermont Oxford Network (established 1988), which is dedicated to improving the quality of neonatal intensive care unit care,<sup>34</sup> and the Children’s Oncology Group (established 1998), which focuses on clinical trials of new therapies, as well as studies of how to improve the delivery of existing therapies for pediatric cancer. The common themes drawn from these collaborative pediatric research networks are an unrelenting commitment to collecting high-quality data, continuously evaluating and proving their value to clinicians making in-the-trenches decisions, and the long-term engagement of the participants and their institutions to sustaining the network.

The BTS method of collaborative improvement was developed by the Institute for Healthcare Improvement to enable collective learning.<sup>35</sup> The BTS model provides an operational framework to enable large-scale application of quality improvement methods by multiple care teams from hospitals or practices to improve care in a focused topic area.<sup>36</sup> It entails a structured process of alternating learning sessions and action periods. At ImproveCareNow learning

**The PDSA Cycle**



FIGURE 3. Plan-Do-Study-Act (PDSA) cycles. Reprinted with permission from Langley G, Nolan K, Nolan T, et al. *The Improvement Guide. A Practical Approach to Enhancing Organizational Performance*. San Francisco: Jossey-Bass; 1996. Reprinted with permission of John Wiley & Sons, Inc.

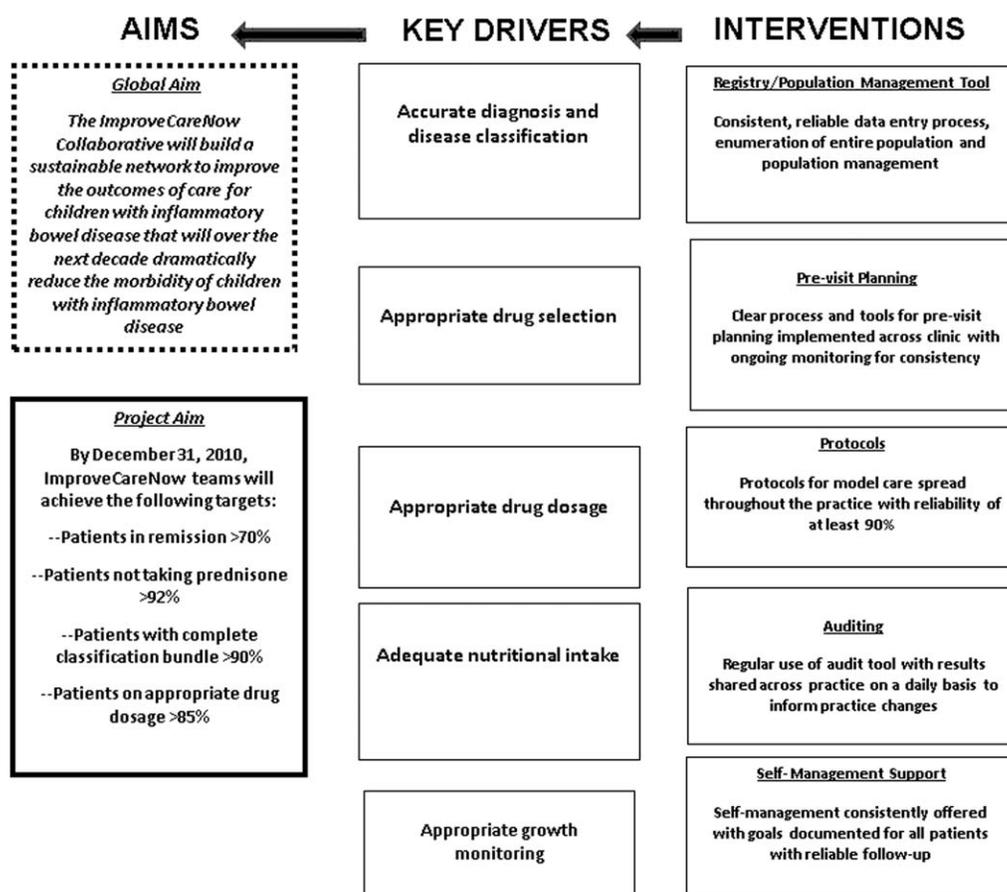


FIGURE 4. Key driver diagram.

sessions, multidisciplinary teams come together to learn and discuss components of IBD care and plan changes. Nationally recognized quality improvement experts provide the training, tools, and support required to redesign systems and incorporate improvements in care into daily practice. Mutual learning, team motivation and empowerment, measurable and achievable targets, knowledge and skills in managing data and change, and plans for sustainable improvement and dissemination are emphasized.<sup>37</sup> During the action periods, teams test and implement changes in their local settings and collect data to measure the impact of the changes.<sup>36</sup> Communication is multimodal and involves transparent sharing of performance data. Teams submit data and progress reports for the entire collaborative to review. The ImproveCareNow extranet website contains tools and reports that sites can download. There is a listserv, monthly all-site conference calls, and semiannual webcasts in which teams from all of the sites gather for learning and sharing. Tools developed and tested by each site are shared with all of the other participating sites, enabling everyone to benefit from the experiences of all sites.

### NETWORK AREAS OF EMPHASIS

Initial activities of the network concentrated on measuring, standardizing, and improving care delivery and outcomes using a complete population registry of patients seen at each site. ImproveCareNow sites focus on several key drivers of good chronic care, as illustrated in Figure 4, using tools which include the creation of chronic care registries and population management review, previsit planning, protocols, decision support, development of self management tools, and auditing.

#### Patient Registry for Performance Measurement and Population Management

Each site is developing improved clinical information systems to monitor patient care processes and clinical outcomes. All IBD patients are enrolled in a patient registry, with common data elements providing baseline and follow-up data on patient demographics, disease characteristics, disease activity, testing, treatment, and clinical course. This allows participants to assess the impact of system changes on patient outcomes.

Data about the patient, disease status, and the care provided are collected during each encounter. Currently, ImproveCareNow network sites collect data using structured clinical encounter forms. After a site joins ImproveCareNow, it adapts its encounter forms (using examples from other sites) to structure them to capture all required data elements. The adaptation and testing process is supported by ImproveCareNow quality improvement training and coaching as part of the implementation process. Currently, data entry occurs via web-based data capture into an electronic FDA-validated registry hosted by Clinicpace Worldwide. At the end of each month, data from the current and previous months are extracted and analyzed to create three reports with tables and control charts<sup>38</sup> that are distributed via a password-protected website: 1) measures of process and outcomes, 2) remission rates, and 3) detailed patient information necessary for population-based care management and patient tracking. Each report contains information about the performance of the individual site and summary information for all sites combined. All performance data are shared transparently, enabling sites to identify those achieving unusually good performance so they can learn from one another. When each practice site receives its reports, its multidisciplinary team reviews the data tables and graphs to identify gaps between its goals and its actual performance, directing the next set of PDSA cycles. Some sites will also analyze the data at the level of the individual providers and share that information within their practice.

The population management report enables each site to examine, in detail, the care provided to its entire IBD population. Data from the centralized registry are used to create a Microsoft Excel-based interactive report that provides detailed, patient-level information across multiple categories (e.g., number of patients in remission, number in steroid-free remission, number receiving steroids, thiopurines, or antitumor necrosis factor antibodies, patients with growth or nutritional failure, etc.). By clicking on any category, all of the patients for that site in that category are identified, along with multiple clinical variables pertaining to that patient. This allows ongoing, targeted intervention and monitoring of at-risk patients between clinic visits.

### Previsit Planning and Use of Protocols

Each site is asked to establish a process for previsit planning so that upcoming patient visits can be identified and planned in advance. Planning most often includes assessing medication dosing, reviewing growth and nutritional status, and arranging for a dietician or endocrinology consultation if needed, confirming that monitoring laboratory studies have been completed regularly, and reviewing ongoing concerns as of the last visit. Sites may also choose to review any number of other relevant issues, such as immunization status, bone density testing, and/or ophthalmol-

ogy examinations. Tools for previsit planning have been developed and shared across practices and clinics to facilitate this process.

### Decision Support

Several IBD-specific decision support tools have been developed and implemented. An algorithm was developed to assess nutrition and growth status at each patient visit and improve the management of patients with unsatisfactory results. Subsequently, the ImproveCareNow Model IBD Care guideline was developed to standardize diagnosis, disease monitoring, and treatment. The guideline was developed by integrating evidence with expert consensus and emphasizes recommendations for immunomodulator and biological therapies. Next, a physician global assessment tool was developed to standardize assessment and classification (inactive, mild, moderate, or severe) of disease severity at each patient visit. Further decision support tools are under development.

### Self-management

Patient self-management, including adherence with follow-up appointments and prescribed therapy, plays a key role in outcomes in chronic disease.<sup>39–44</sup> Members of the collaborative currently are developing a self-management workbook for all children and adolescents with IBD. This workbook provides education on important topics in IBD, but, more important, encourages patients and families to assume progressively more responsibility for their own care as they transition from childhood to adulthood, including a series of simple tasks to encourage this process.

### Auditing

The network encourages sites to use auditing to increase the reliability of new care delivery processes. Auditing may include assuring completion of specific process measures, such as completion of case report forms, previsit planning, or population management review. Auditing may also entail assessing site adherence with developed guidelines. For example, a site may review the last 10 patients seen to determine whether the relevant components of the model care guidelines were completed for each patient. Patients who did not meet all components of the guidelines would be investigated further (referred to as a failure analysis) to determine what underlying issues led to any failures so that those issues can be systematically addressed.

## RESULTS

### Collaborative Growth

In 2007, 10 practice sites agreed to form the PIBD-Net Trailblazer Improvement Collaborative to improve the care and outcomes of children with IBD. The Network

grew to 16 sites in 2009; in 2010, patients are being enrolled at 24 sites. As of 2009, over 2500 patients have been enrolled and data from over 7500 visits have been collected and analyzed.

### Preliminary Findings

Results of the impact of network activities on the outcomes of care will be reported separately in future publications. However, preliminary findings have suggested improvements in both the process of care (e.g., appropriate medication dosing and completion of a classification bundle that includes the patient's diagnosis, disease activity, distribution and phenotype, growth status, and nutrition status) and outcomes, such as the percentage of patients in remission. These initial results suggest that practice sites are learning how to build and maintain an infrastructure to successfully perform quality improvement.

### External Recognition

The Network has received the support of the ABP and the Alliance for Pediatric Quality. Funding to support research has been obtained through the Centers for Education and Research in Therapeutics in the Agency for Healthcare Quality and Research and a recently awarded grant from the NIH director's office for transformative research in chronic illness care. The ABP has designated participation in ImproveCareNow as qualifying for credit for MOC.

### CHALLENGES

Multiple challenges exist to the integration and spread of a large-scale quality improvement network such as this. First, sites must agree on well-defined process and outcome measures, despite a paucity of data on which measures most influence the quality of care. Once agreement is achieved on those measures, collaborators must reliably collect data and assure the quality of that data, which requires a substantial commitment of time and resources. The ability to commit resources to an improvement collaborative may also result in variation in the implementation of specific interventions, which can result in varying outcomes between centers. ImproveCareNow is actively seeking to address each of these issues in order to allow for spread of the network to additional sites, to assure its sustainability, and ultimately to improve the outcomes of patients with IBD.

### A VISION FOR THE FUTURE

The Institute of Medicine (IOM) has recently promoted the concept of a learning healthcare system. Core concepts of the IOM vision include a focus on continuously improving outcomes; learning as a partnership enterprise among patients, clinicians, and researchers; advancing

clinical data as a shared asset; building comparative effectiveness research into practice; and a governance model that promotes diverse leadership.<sup>45</sup> ImproveCareNow is an example of how parts of the IOM's vision for the learning healthcare system might be made operational.

### ACKNOWLEDGMENT

The authors thank Pamela Schoettker, MS, medical writer, Center for Health Policy and Clinical Effectiveness, Cincinnati Children's Hospital Medical Center for editorial assistance.

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