

# IMPROVECARENOW

*improving lives through collaborative medicine*

**ImproveCareNow is a collaborative chronic care network of 109 care centers, including 97 in 39 states and the District of Columbia, as well as in England, Qatar and Belgium, where clinicians, researchers, patients and families are working together to transform the health, care and cost for 30,000 children and youth with Crohn's disease and ulcerative colitis. Since early 2008 the proportion of our patients who are in remission has progressively increased from 55% to over 80%. If all children and youth in the US with inflammatory bowel disease were participating in ImproveCareNow, over 10,000 more would be in remission now. ImproveCareNow is a learning health network for the acceleration of innovation, discovery and the application of new knowledge. ImproveCareNow is supported by the American Board of Pediatrics, the Alliance for Pediatric Quality, the Centers for Education and Research in Therapeutics, the US Agency for Healthcare Research and Quality, the National Institutes of Health, the Patient Centered Outcomes Research Institute, Crohn's & Colitis Foundation, pharmaceutical companies and participating care centers, and collaborates with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition and the FDA. ImproveCareNow has been awarded the prestigious Drucker Prize for "change that creates a new dimension of performance." Health care organizations, physicians, patients and families can play a vital role in expanding ImproveCareNow so all children and youth with IBD can participate in the ImproveCareNow Network.**

The ImproveCareNow Network is working successfully to improve the quality of care delivered to children and youth with inflammatory bowel disease (IBD) at clinic and office centers. Begun in January 2007, the number of participating practice centers has increased from 8 to 109. Based on rankings by USNWR, nine of the 10 Honor Roll children's hospitals, and 45 of the top 50 pediatric gastroenterology programs, are participants in ImproveCareNow. The initial focus has been to build a quality improvement (QI) infrastructure at each center; develop and implement the recommendations of the ImproveCareNow Model IBD Care Guideline; to measure and report the performance at each center and all centers; identify gaps between the recommended care and the care actually provided; and implement quality improvement projects to close the gaps.

Centers have been applying innovative quality improvement methods to improve initial diagnostic testing and evaluation; standardize the classification of the severity, phenotype and extent of disease; improve the detection and treatment of poor nutrition and growth; and improve the use of immunomodulator and other medications. Each center is developing improved clinical information systems and a population registry to improve documentation, monitoring and care.

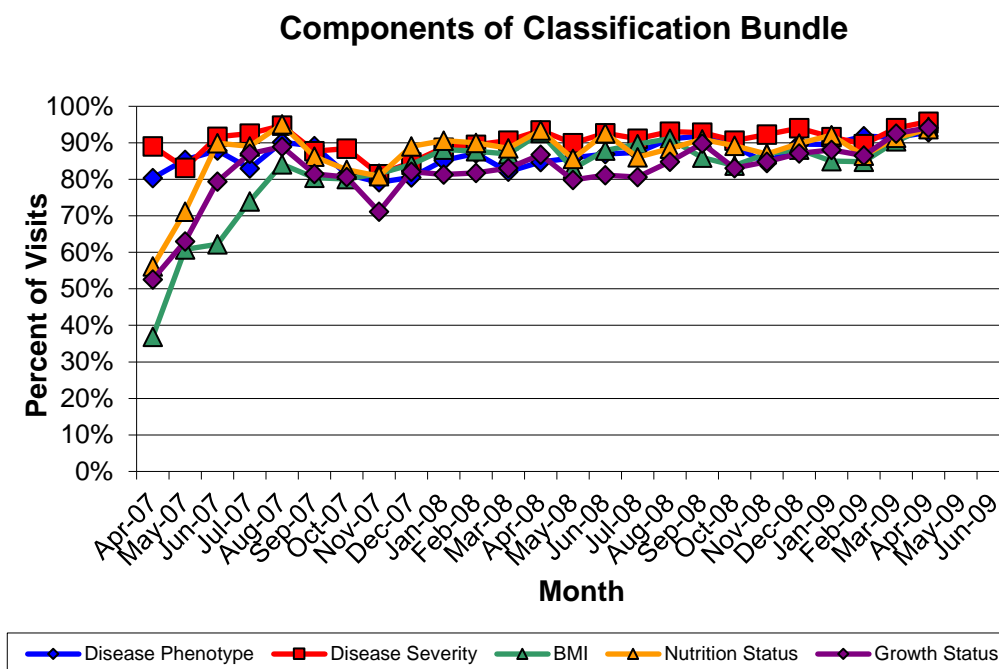
Currently 40,000 patients are registered and data from 290,000 visits have been collected and analyzed. Under the guidance of experts in quality improvement and care delivery, participating centers have been collecting and sharing clinical data about their patients and testing specific changes in the care of children with IBD to determine how to redesign and incorporate improvements in care into their daily practice. Each center is contributing an annual participation fee and a commitment to engage a multi-professional QI team in on-site work, web-based data entry and participation in collaborative learning sessions with other centers.

ImproveCareNow has the largest and fastest growing pediatric IBD registry in the world. ImproveCareNow centers have more than half of the pediatric gastroenterologists who care for IBD patients. ImproveCareNow, Inc., a 501(c)3 with a national office at the University of Vermont, works closely as a strategic partner with the Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. Each year more than \$10 million is invested in ImproveCareNow activities, from center participation fees, philanthropy, grants and in-kind



contributions of participating centers (including physician and staff time and attendance at twice-yearly Community Conferences). ImproveCareNow has over 40 staff (15 full time equivalent staff). In addition, there are 100 researchers and volunteers, and 250 staff at participating centers who also contribute to ImproveCareNow.

Shown in the following graph are examples of improvement in process measures: classifying the severity of disease at each patient visit; calculating the body mass index (BMI) and plotting it on a growth chart; and assessing and classifying the nutritional and growth status at each visit.

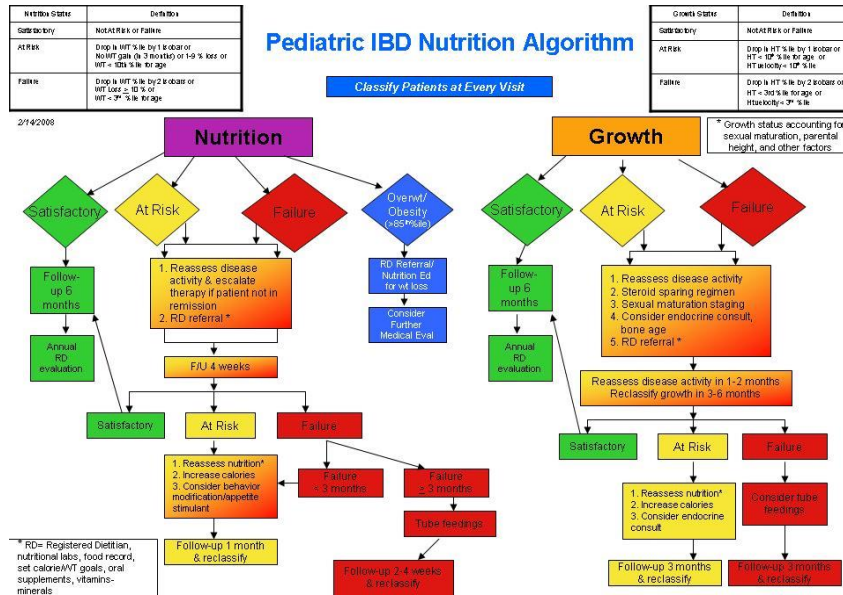


The reliability of disease classification and assessment increased from ~40% to ~90%. This data indicates that the practice centers have learned how to build and maintain an infrastructure to successfully perform quality improvement.

The ImproveCareNow Network has developed an algorithm, shown in the figure above, to improve the management of patients with unsatisfactory nutrition or growth. Children classified with unsatisfactory growth decreased by 60%. In addition, children taking prednisone decreased by 30%.

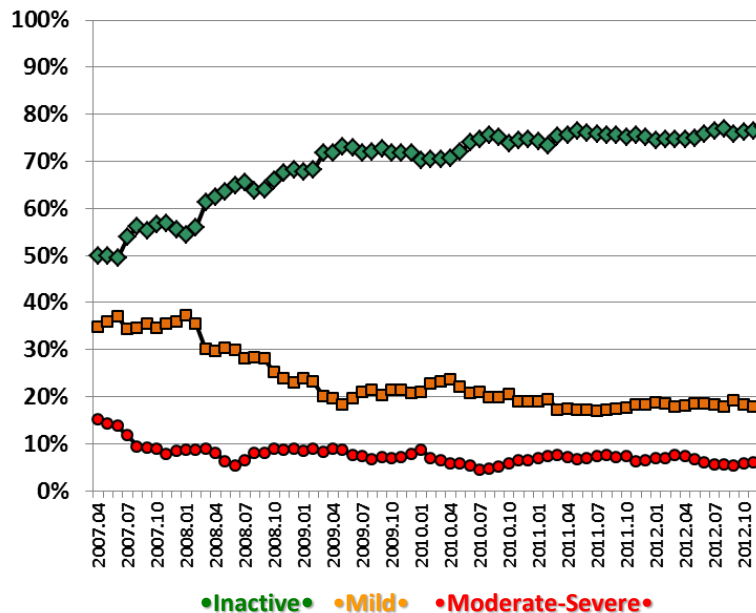
### Tools and outcomes

We currently use 5 major interventions to improve care deliver: [1] registration of all IBD patients in a registry with data quality management, [2] consistent reliable care based on the ImproveCareNow Model IBD Care guidelines, and the application of reliability methods, [3] population management, [4] pre-visit planning, and [5] self-management support.



We have been measuring and monitoring clinical outcome, primarily with the Physician Global Assessment, to assess disease severity at each patient visit and to classify it as inactive, mild, moderate or severe. A graph of the percentage of Crohn's disease and ulcerative colitis patients with inactive disease, shown below, demonstrates an increase from 50% to 79%, with decreases in mild, moderate and severe disease activity.

**% of Patients by Disease Status (cumulative)**



We have expanded our Model IBD Care Guidelines for Consistent Reliable Care and revised our key performance measures to emphasize recommendations for immunomodulator and biological therapies. Our focus is on increasing the percentage of patients with inactive disease; sustained remission (greater than 12 months without a relapse); prevention of relapses; reducing the number of patients receiving corticosteroids; and avoiding adverse effects from therapy. By working together, participants of the ImproveCareNow Network have created a model

that pediatric gastroenterology practices can adopt. By developing, implementing and sharing the Model IBD Care Guidelines, participants in the ImproveCareNow Network are leading the improvement of pediatric IBD care.

### **How does the ImproveCareNow Network work?**

During each patient encounter at the office or clinic, data is collected about the patient, disease status and care provided at the visit. After the visit, using web-based data entry, each patient's data entered into the ImproveCareNow database in a secure server at Cincinnati Children's Hospital Medical Center. All of the data are analyzed and reports with tables and graphs are prepared and made available to each practice center: a report of the key clinical measures of process and outcomes; the Population Management Report with detailed patient information; and a data quality report. Each report contains information about the performance of the individual center and summary information of all of the centers combined. Reports are now automated and are readily available at any time to every center with updated clinical data on every patient.

When each center obtains its reports, its core QI team reviews the data, tables and graphs to identify gaps between its goals and actual performance. The center then implements Plan-Do-Study-Act quality improvement cycles to close the gaps, collecting data to determine the effectiveness of the changes they make. With this iterative process of continuous quality improvement, changes are made in the way care is delivered at the center, resulting in improvements in the care provided.

Each center works to develop, test and implement tools for change. Effective tools are shared with all of the participating centers, enabling all centers to benefit from the work of other centers. All centers are both learners and teachers. To facilitate communication among the centers, the ImproveCareNow web resource center contains tools and reports that centers can download. In addition, there is a listserv, monthly live webinars, and semi-annual learning sessions in which teams from all of the centers gather for learning and sharing.

We are implementing standardized electronic data collection forms and a process of electronic data transfer, in which data from centers with electronic health records is transferred electronically, rather than manually, to the ImproveCareNow registry database.

### **Supporters**

The ImproveCareNow Network is supported by the Centers for Education and Research in Therapeutics of the US Agency for Health Care Quality and Research, the National Institutes of Health, the Patient Centered Outcomes Research Institute, Crohn's & Colitis Foundation, pharmaceutical companies and by participating care centers. The ImproveCareNow Network has been selected by the Alliance for Pediatric Quality as one of the four most successful pediatric improvement initiatives. The American Board of Pediatrics has designated participation in the ImproveCareNow Network as qualifying for credit for Maintenance of Certification. The participating centers consist of university practices, multispecialty groups, children's hospitals and private practices.

ImproveCareNow offers an exciting model for using quality improvement tools for addressing other illnesses. ImproveCareNow is a laboratory for a study of the use of social networking to improve chronic illness care. Funded by a Transformative R01 grant from the National Institutes of Health, ImproveCareNow has been the center of a study of how to create a Collaborative Chronic Care Network of patients, families, clinicians and researchers working together to improve the care of children with chronic illness. With funding from the Agency for Healthcare Research and Quality, ImproveCareNow has built an enhanced registry with advanced informatics for quality improvement and comparative effectiveness research. With funding from the Patient Centered Outcomes Research Institute, ImproveCareNow is developing better ways to engage patients and families, creating tools for patient reported outcomes, and establishing a National Pediatric Learning Health System. In addition, ImproveCareNow is collaborating with the North American Society for Pediatric Gastroenterology, Hepatology



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and Nutrition on a patient self-management support project, and with the US Food and Drug Administration on drug safety.

ImproveCareNow has been fortunate to work with award winning filmmaker Jesse Dylan, and his creative teams at Lybba and WONDROS, to share the story of the ImproveCareNow Network. Watch our inspirational videos at <http://bit.ly/joinICN> and <http://bit.ly/gofullcircle>. You can also see a short clip of ImproveCareNow accepting the 2016 Drucker Prize at <http://www.drucker.institute/nonprofits/#>, and a video of reflections on ImproveCareNow's first decade at <https://www.youtube.com/watch?v=R2IsAgEBcCE/>.

**The goals of the ImproveCareNow Network** are to enable the pediatric IBD team at each center to:

1. Learn how well their patients are doing, compared to patients at other centers
2. Learn about the Improvement Model and the Chronic Illness Care Model as they apply to pediatric IBD
3. Receive training in QI and rapid cycle changes in pediatric IBD
4. Establish systems for measuring and tracking performance at their center
5. Receive the most current recommendations for the management of IBD
6. Receive materials for use in clinical practice
7. Improve the care of patients and patient satisfaction
8. Create quality care delivery systems for a new or existing IBD Center
9. Provide input into the establishment of best practices
10. Contribute to the advancement of clinical practice at their center and nationally
11. Receive a certificate of participation
12. Satisfy a requirement for maintenance of certification by the American Board of Pediatrics

**The ImproveCareNow Network agrees to:**

1. Operate the Network with effective organizational, communication and leadership skills, working consistently to achieve the goals of the Network
2. Provide an effective onboarding process that assists each center in getting started and learning the basics of QI
3. Organize and present a learning session for all of the centers twice a year
4. Teach centers how to apply a systems framework for IBD to the care of patients
5. Teach methods for implementing and testing improvements in care
6. Develop, implement and manage a structured framework for testing changes in care delivery across all participating centers
7. Coach centers in implementing and evaluating changes
8. Provide evidence-based information on IBD and tools, forms, and other aids to help with implementation of changes
9. Coordinate communication across all centers to provide participants with analyses about the effectiveness of changes and about the work of their colleagues during the Improvement Network
10. Develop measures for tracking and a repository of interventions for application and testing.
11. Provide secure HIPAA-compliant data management, including web-based data entry, data storage, data analysis, reports and analyses

**Each center agrees to:**

1. Obtain the support of the administrative leadership at the center for this Improvement Network



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2. Have a multi-professional QI team (e.g., physician, nurse or nurse practitioner and staff), including a physician leader (a “physician champion”), that will organize, lead and advocate for improvement efforts at the center
3. Enter relevant clinical data about all patients receiving care at the center during the Network into the Network database, to use as a clinical management registry, to track patients and their care at each and all of the centers, and to compare care among all of the centers
4. Enable team members, including the physician leader, to attend all learning sessions, providing support for their travel and accommodations
5. Provide resources and support to the center team, including time to devote to testing and implementing changes in the center
6. Perform pre-work activities to prepare for workshops
7. Link the goals of the Network to the goals of the center
8. Implement changes in one or more of the target areas of IBD care and perform tests of the changes
9. Communicate in a timely fashion, including electronically, with the Network organizers
10. Participate in conference calls, web casts and listserv activities to communicate and share with and learn from others
11. Make defined measurements at least monthly and plot them over time for the duration of the Network, and share the results with the other centers
12. Share information with Network participants through a monthly report that includes details of changes made and data to evaluate the impact of these changes
13. Have computers, internet access, e-mail, and needed software for use during the improvement collaborative
14. Obtain IRB approval through either participation in the ImproveCareNow central IRB or local IRB
15. Execute the official Participation-Data Use Agreement and Business Associates Agreement
16. Pay an annual participation fee.





## Current Participating Care Centers

Advocate Children's Hospital, Oak Lawn IL  
 Advocate Children's Hospital, Park Ridge IL  
 Akron Children's Hospital, Akron OH  
 American Family Children's Hospital, Madison WI  
 Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago IL  
 Arkansas Children's Hospital, Little Rock AR  
 Arnold Palmer Hospital for Children, Orlando FL  
 Baptist Children's Hospital, Miami FL  
 Barbara Bush Children's Hospital at Maine Medical Center, Portland ME  
 Baystate Medical Center, Springfield MA  
 Bon Secours St. Mary's Children's Hospital, Richmond VA  
 Boston Children's Hospital, Boston MA  
 Boys Town National Research Hospital, Boys Town NE  
 Bronson Children's Hospital, Kalamazoo MI  
 Cambridge University Hospitals (Addenbrookes), Cambridge England  
 Cardinal Glennon Children's Medical Center, St. Louis MO  
 Carilion Clinic Children's Hospital, Roanoke VA  
 Children's Healthcare of Atlanta at Egleston/Emory University, Atlanta GA  
 Children's Healthcare of Atlanta at Scottish Rite - GI Care for Kids, Atlanta GA  
 Children's Hospital and Medical Center Omaha, Omaha NE  
 Children's Hospital at Dartmouth, Lebanon & Manchester NH  
 Children's Hospital at Erlanger, Chattanooga, TN  
 Children's Hospital at Lehigh Valley Health Network, Allentown PA  
 Children's Hospital Colorado, Aurora CO  
 Children's Hospital of Illinois - University of Illinois Peoria, Peoria IL  
 Children's Hospital of Los Angeles, Los Angeles CA  
 Children's Hospital of Pittsburgh of UPMC, Pittsburgh PA  
 Children's Hospital of Richmond at VCU, Richmond VA  
 Children's Hospital of The King's Daughters, Norfolk VA  
 Children's Hospital of Wisconsin, Milwaukee WI  
 Children's Memorial Hermann Hospital - UT Houston, Houston TX  
 Children's Mercy, Kansas City MO  
 Children's National Health System, Washington DC  
 Children's of Alabama, Birmingham AL  
 CHOC Children's, Orange CA  
 Cincinnati Children's Hospital Medical Center, Cincinnati OH  
 Clinique Saint Joseph  
 Cook Children's Medical Center, Fort Worth TX  
 Dayton Children's Hospital, Dayton OH  
 Dell Children's Medical Center of Central Texas, Austin TX  
 Duke Children's Hospital and Research Center, Durham NC  
 Floating Hospital for Children at Tufts Medical Center, Boston MA  
 Great Ormond Street Hospital, London England  
 Greenville Health System, Greenville SC  
 Helen DeVos Children's Hospital, Grand Rapids MI  
 Holtz Children's Hospital at UM-Jackson Memorial Medical Center, Miami FL  
 Joseph M. Sanzani Children's Hospital Hackensack University Medical Ctr, Hackensack, NJ  
 Jessa Ziekenhuis, Belgium  
 Kentucky Children's Hospital, Lexington, KY  
 Kravis Children's Hospital at Mount Sinai, New York NY  
 Le Bonheur Children's Hospital, Memphis TN  
 Levine Children's Hospital, Charlotte NC  
 MassGeneral Hospital for Children, Boston MA  
 Mayo Clinic, Rochester MN  
 Monroe Carrell Jr. Children's Hospital at Vanderbilt, Nashville TN  
 Multicare Mary Bridge Children's Hospital, Tacoma WA  
 MUSC Children's Hospital, Charleston SC  
 Nationwide Children's Hospital, Columbus OH  
 Nemours Children's Specialty Care, Jacksonville FL  
 Nemours Children's Health System, Wilmington DE  
 Nemours Children's Hospital, Orlando FL  
 New Hampshire's Hospital for Children, Manchester NH  
 New York-Presbyterian Phyllis and David Komansky Center  
 for Children's Health/Weill Cornell Medical Center, New York NY  
 Nicklaus Children's Hospital, Miami FL  
 NW Pediatric Gastroenterology - Randall Children's Hospital, Portland OR  
 NYU Langone Medical Center Hassenfeld Children's Hospital, New York NY  
 Ochsner Hospital for Children, New Orleans LA  
 OHSU Doernbecher Children's Hospital, Portland OR  
 Oklahoma University Medical Center, Oklahoma City OK  
 Pediatric Gastroenterology & Nutrition Associates, Las Vegas NV  
 Pediatric Specialists of Virginia, Fairfax VA  
 Penn State Hershey Children's Hospital, Hershey PA  
 Phoenix Children's Hospital, Phoenix AZ  
 Providence Sacred Heart Children's Hospital, Spokane WA  
 Rady Children's Hospital, San Diego CA  
 Rainbow Babies and Children's Hospital, Cleveland OH  
 Riley Hospital for Children, Indianapolis IN  
 Seattle Children's Hospital, Seattle WA  
 Sidra Medical and Research Center, Doha Qatar  
 St. Christopher's Hospital for Children, Philadelphia PA  
 St. Louis Children's Hospital - Washington University, St. Louis MO  
 Stanford Children's Health, Palo Alto CA  
 Texas Children's Hospital, Houston TX  
 UC Davis Children's Hospital, Sacramento CA  
 UCSF Benioff Children's Hospital, Oakland CA  
 UCSF Benioff Children's Hospital, San Francisco CA  
 UF Health Pediatric Gastroenterology, Hepatology & Nutrition, Gainesville FL  
 University of Iowa Stead Family Children's Hospital, Iowa City IA  
 University of Michigan - C.S. Mott Children's Hospital, Ann Arbor MI  
 University of Minnesota, Minneapolis MN  
 University of North Carolina at Chapel Hill, Chapel Hill NC  
 UT Southwestern/ Children's Health, Dallas TX  
 The Children's Hospital at Montefiore, New York NY  
 The Children's Hospital of Philadelphia, Philadelphia PA  
 Universitair Ziekenhuis of Antwerp, Belgium  
 Universitair Ziekenhuis Brussel, Belgium  
 Universitair Ziekenhuis Gent, Belgium  
 Universitair Ziekenhuis Leuven, Belgium  
 Cliniques Universitaires Saint-Luc, Belgium  
 Universite Libre Bruxelles Reine Fabiola, Belgium  
 University of New Mexico Children's Hospital, Albuquerque NM  
 University of Vermont Children's Hospital, Burlington VT  
 University of Virginia Children's Hospital, Charlottesville VA  
 Upstate Golisano Children's Hospital, Syracuse NY  
 Valley Children's Hospital, Madera CA  
 Yale-New Haven Children's Hospital, New Haven CT  
 Zuid Oost Limburg, Belgium

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Name, MD, Executive Network Director  
 Name, MD, Executive Scientific Director



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