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# ADVANCES IN TRANSLATIONAL SCIENCE

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# Translating Improved Quality of Care Into an Improved Quality of Life for Patients With Inflammatory Bowel Disease

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**The term *quality of care* has been interpreted in different ways in medicine. Skeptics of the quality movement insist that checkboxes and government and payer oversight will not lead to better patient outcomes. Supporters refer to areas in medicine in which quality improvement efforts have led to improved survival, such as in cystic fibrosis and cardiovascular disease. For quality improvement to be effective, the process demands rigorous documentation, analysis, feedback, and behavioral change. This requires valid metrics and mechanisms to provide dynamic point-of-care (or close to point of care) feedback in a manner that drives improvement. For inflammatory bowel disease, work has been performed in Europe and the United States to develop a framework for how practitioners can improve quality of care. Improve Care Now has created a sophisticated quality improvement program for pediatric patients with inflammatory bowel disease. The American Gastroenterology Association has worked within the National Quality Strategy framework to develop quality measures for patients with inflammatory bowel disease that have been incorporated into Federal programs that are moving Medicare reimbursement from a volume-based to a value-based structure. The Crohn's and Colitis Foundation of America is initiating a quality intervention program that can be implemented in community and academic practices to stimulate continual improvement processes for patients with inflammatory bowel disease. All of this work is intended to make quality improvement programs both feasible and useful, with the ultimate goal of improving quality of life for our patients.**

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When it comes to providing care to patients, the word "quality" has several different connotations. The negativists push back with questions of why the government and other payers should decide if they are providing good care to their patients and penalizing them if they have not checked the appropriate boxes to prove that they are quality doctors. They typically suggest that the imposition of quality measures disrupts the art of medicine and makes the precious minutes at an office visit more about accountability than about thoughtfully delivered health care. Those supportive of the quality movement see it through a different lens. They believe that the word quality implies consistent delivery of evidence-based care to all patients, and that decreasing variability of how care is delivered ultimately will lead to better individual outcomes, a healthier population, and reduced costs (the "Triple Aim").[1]

These different definitions often are considered as distinct approaches to quality of care. However, both actually are important in how we improve the quality of care delivered to our patients through a rigorous process of documentation, analysis, feedback, and behavioral change. The Institute of Medicine defines quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[2] This definition does not say anything about checkboxes, financial reward, or penalties, but does imply that some measurement will be performed to determine whether quality care is being delivered and if health outcomes are improving. The key to success lies in our ability to develop valid metrics and mechanisms to provide dynamic point-of-care (or close to point of care) feedback in a manner that drives improvement. For example, dynamic point-of-care feedback is provided as you see a patient, such as red flag alerts, pop-ups, or other instantaneous reminders. This is in contrast to a checkbox submitted to a registry, with feedback on performance coming 6 or more months later.

Other fields in medicine have been successful in developing programs to improve the quality of care for patients as a result of defining valid metrics, developing a reporting infrastructure, comparing provider results against best practice, and aggregating results in ways that promote continual improvement. A notable example has been the Quality Care Initiative developed by the Cystic Fibrosis (CF) Foundation, in which more than 100

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***Abbreviations used in this paper:*** **AGA, American Gastroenterological Association; BTE, Bridges to Excellence; CCFA, Crohn's and Colitis Foundation of America; CF, cystic fibrosis; CMS, Centers for Medicare and Medicaid; GI, gastrointestinal; IBD, inflammatory bowel disease; ICN, Improve Care Now; MAP, Measures Application Partnership; NNECDSG, Northern New England Cardiovascular Disease Study Group; NQF, National Quality Forum; NQS, National Quality Strategy; PQRS, Physician Quality Reporting System.**

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centers that provide CF care in the United States participate.[3] When this program was developed, clinicians first defined the clinical microsystem of who should share accountability for patients' health and survival. They concluded that care depended on more than physicians and included patients, parents, midlevel providers, nurses, dieticians, and social workers. They next established quality indicators most closely related to important health outcomes, including measurement of body mass index, forced vital capacity, and mortality. Then, they made a critical decision (after several years of debate). As a group, it was decided that both measurement and transparent reporting of health outcomes at the level of a care center was needed to truly drive improvement and provide quality transparency for patients. In fact, at the CF Foundation website (http://www.cff.org) after a 1-minute registration process anyone can explore quality metrics for every center throughout the country. For example, the volume of patients seen at each center is listed, in addition to the mean forced expiratory volume, mean body mass index, and other measures. One also can see trends for those measures over a 5-year period, and, most interestingly, how one center compares with another in the country. Perpetual improvement in care is an inherent part of the plan, and centers work together during regular collaborative meetings to determine approaches that are more successful than others. Since this program started, life expectancy for people with CF at participating centers has increased from a median predicted survival of 27.7 to 28.6 years between 1994 and 1999 (average, 0.18 y gained annually), and recently to a median of 37.4 years in 2007 (average, 1.1 y gained annually).[3]

The approach by the CF Foundation (measurement, analysis, and transparent reporting) also has been used by others, including the Northern New England Cardiovascular Disease Study Group (NNECDSG). Through a carefully planned collaborative training and feedback program over a 2-year period, the regional consortium reported a 24% reduction of in-hospital coronary artery bypass graft mortality.[4] Albeit different disease states, it is not a huge stretch to use what these other groups have done to model how we collaboratively can improve the quality of care delivered to our patients with inflammatory bowel diseases (IBDs).

## What Has Been Done for Quality of Care in Inflammatory Bowel Disease?

Over the past decade, efforts to improve quality of care in IBD patients have appeared in many regions of the world. After an audit in 2006 showed widespread variation in care of patients with IBD in the United Kingdom, a multidisciplinary panel developed a set of IBD Standards that defined key performance indicators and guidelines for quality care. Although these standards are not all based on firm (high-quality) evidence, they do reflect a general multidisciplinary consensus on what defines quality care for patients with IBD in the United Kingdom, and include both structural standards (the setting in which care is delivered; eg, the number of specialty providers that should be available for a given population) and measures reflecting processes of care, with an emphasis on patient-centered care.[5]

The first group to develop an outcomes registry designed to enhance quality of IBD care in the United States was the Improve Care Now (ICN) consortium. This is a collaborative of pediatric IBD centers that has grown to nearly 50 centers that collectively include approximately one third of all pediatric gastroenterologists in the United States and now contains measures from more than 10,000 unique pediatric IBD patients. By using a shared database, ICN participants enter prospective data on all patient visits. Monthly reports are generated by the central data repository and are sent back to individual sites where there are weekly site meetings and regularly scheduled learning sessions when the entire collaborative gets together to share knowledge. By using the physician's global assessment, ICN participants have documented an increase in remission rates from 55% to 75% over the past few years.

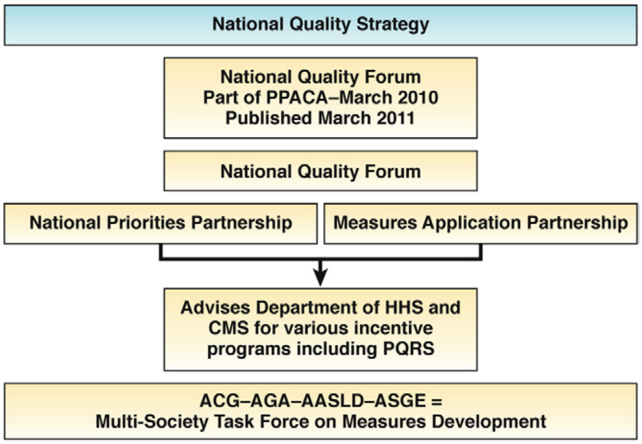

**Figure 1.** The NQS was defined in the PPACA that was signed into law in March 2010. AASLD, American Association for the Study of Liver Disease; ACG, American College of Gastroenterology; ASGE, American Society of Gastrointestinal Endoscopy; HHS, Department of Health and Human Services; PPACA, Patient Protection and Affordable Care Act.

The American Gastroenterological Association (AGA) in cooperation with several other gastrointestinal (GI) societies has led our specialty in developing quality metrics for treatment of hepatitis C, gastroesophageal reflux disease, appropriate use of colonoscopy, and, most recently, for IBD care. The AGA has worked through the measure development process as outlined by the National Quality Strategy (NQS) (Figure 1). The NQS was defined in the Patient Protection and Affordable Care Act that was signed into law in March 2010. Th NQS, first released in March 2011, is overseen by the Department of Health and Human Services and is implemented through the National Priorities Partnership. The National Priorities Partnership is a partnership of more than 50 quality improvement organizations, convened by the National Quality Forum (NQF). Specific measures can be developed by anyone, however, the process of endorsement for use in incentive reimbursement programs (both Federal and commercial) now is coordinated and defined by the Measures Application Partnership (MAP), a process given statutory authority within the Patient Protection and Affordable Care Act and managed by the NQF. Although the MAP is the gold standard for measures endorsement, Federal programs such as the Centers for Medicare and Medicaid's (CMS) Physician Quality Reporting System (PQRS) can include measures not endorsed by the NQF. In fact, more than half of the measures in PQRS are not NQF-endorsed (although the intent over time is to synchronize all such measures within the MAP and NQS).