



WHAT IS THE PROJECT?

Inflammatory bowel disease (IBD) affects 1.6 million Americans. Due to its chronic nature and high disease burden, IBD can have a profound effect on patients' day-to-day lives, including a large financial burden and, for some patients, chronic opioid use. Uncontrolled IBD can severely impair a person's physical and emotional well-being, and patients live with stigma, shame, and trauma due to IBD and the inability to predict "flares." Diagnostic and treatment advances can reduce disease burden and improve quality of life and long-term outcomes in IBD. However, quality of care varies, and many patients do not receive multidisciplinary, evidence-based care. Establishing disease-specific, patient-centered measures that focus on symptom management and disease control is essential to improving quality of life and health outcomes for patients with IBD.

This NQF Measure Incubator® project is the first step toward facilitating the development of measures that assess disease activity, symptom management, and quality of life for patients with inflammatory bowel disease.

STRATEGY SESSION

NQF convened a Measure Incubator strategy session with a multistakeholder Expert Panel in May 2019. At this meeting, panelists discussed a range of measures focused on quality of life, evidence-based care, and patient engagement. The Panel emphasized the need for a holistic, multidisciplinary approach to patient care that accounts for individual preferences, encourages shared decision making, and improves health literacy. The Expert Panel identified and prioritized nine measure concepts that could become performance measures for IBD. These concepts focus on integrating routine assessments of quality of life and patient engagement within clinical practice, evidence-based care, and inappropriate use of opioids. Panelists recommended further exploration of innovative tools to gather real-time, accessible, actionable data needed for patient care and performance measurement in IBD.

NQF engaged a broad-based stakeholder group in this Measure Incubator project, including individuals with Crohn's disease and ulcerative colitis, nutritionists, clinicians, payers, researchers, and measure developers.

WHAT IS THE ENVISIONED OUTCOME?

Building on the recommendations from the NQF-convened strategy session, NQF seeks to facilitate the development of one or more measure concepts into fully specified and tested performance measures. NQF will explore funding to support measure development and testing beginning in summer 2019.

This work creates a solid foundation for measures that will improve the quality of life and health outcomes of patients with IBD by ensuring that patients receive holistic, patient-centered care.

NQF is delivering this project through the Measure Incubator with financial support from **Johnson & Johnson Health Care Systems, Inc (JJHCS)**. In accordance with the **NQF Measure Incubator Conflict of Interest Principles**, JJHCS has not influenced the outcomes and activities associated with this project.