Evaluating a Prediction Tool and Decision Aid for Patients with Crohn’s Disease

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Summary: Crohn’s disease is a chronic inflammatory bowel disease that has significant negative impact on the quality of life of an estimated 500,000 Americans. Recent studies indicate that treating Crohn’s with immunomodulator and anti-tumor necrosis factor soon after diagnosis and before complications occur leads to better patient outcomes. However, these medications are associated with life-threatening infections and lymphoma. A challenge of treating Crohn’s disease is identifying patients who will develop severe disease and need medications without over-treating patients who have mild disease. Additionally, patients are often reluctant to begin treatment until the disease becomes more severe.

Dr. Siegel and his research team developed two tools to address these concerns. The first is a statistical model that predicts Crohn’s disease severity for an individual patient based on clinical, serologic, and genetic factors. The second tool is a Web-based decision aid to help patients weigh the benefits and risks of available treatments for Crohn’s disease. These two tools comprise the Crohn’s Disease Shared Decision Making Program.

Specific Aims:

- Validate the previously created Crohn’s disease prediction models. (Upcoming)
- Optimize the Crohn’s Disease Shared Decision Making Program. (Ongoing)
- Study the impact of the Crohn’s Disease Shared Decision Making Program on patients’ treatment choice, persistence with chosen therapy, decision quality, cost of care, and outcomes. (Upcoming)

2012 Activities: The research team is laying the ground work for the project. One component of the start-up activities involves building an interface that will allow patients to interact with the Crohn’s disease prediction model and the decision aid. Another component is developing a data collection strategy that involves Web-based surveys to facilitate efficient followup with patients upon trial initiation. Upon completion of the start-up activities, a cluster randomized controlled trial will be conducted at 15 academic and community clinical sites to compare the two tools with standard of care. The primary outcome is patients’ choice of therapy. Secondary outcomes include the effect of the decisionmaking program on persistence with chosen therapy, decision quality, and the influence on cost of care and clinical outcomes. As last self-reported in the AHRQ Research Reporting System, project progress and activities are on track and project spending is on target.

Preliminary Impact and Findings: There are no findings to date.
**Target Population:** Chronic Care*: Crohn’s Disease

**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to improve health care decisionmaking through the use of integrated data and knowledge management.

**Business Goal:** Knowledge Creation

*This target population is one of AHRQ’s priority populations.*