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Evaluation of Gastrointestinal Patient Reported Outcomes Measurement Information System (GI PROMIS) Symptom Scales in Subjects with Inflammatory Bowel Diseases

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Background: Patient reported outcomes (PROs) are important treatment endpoints in inflammatory bowel diseases (IBD). We evaluated the newly developed gastrointestinal (GI) PRO Measurement Information System (PROMIS) in IBD subjects.

Methods: Crohn's and Colitis Foundation of America's Partners is an Internet-based cohort of IBD subjects. Participants completed surveys, including PROMIS domains and disease activity indices. We used univariate and bivariate analyses to assess 8 GI-PROMIS domains: reflux, swallowing, diarrhea, nausea, belly pain, gas, incontinence and constipation.

Results: The study included 2,378 Crohn's Disease (CD) and 1,455 ulcerative colitis (UC) respondents with a median age of 41 years. Median disease duration was 11 years for CD and 8 years for UC; 57% of CD subjects and 42% of UC subjects were in remission. Compared to subjects in remission, those with active CD reported significantly worse symptoms on all 8 GI-PROMIS domains; the same was observed for UC subjects with the exception of disrupted swallowing. CD and UC subjects with worse quality of life (QoL) reported significantly worse symptoms on all 8 GI-PROMIS domains compared to those with better QoL. CD and UC subjects with more diarrhea, belly pain and gas had significantly poorer psychosocial PROs.

Conclusions: This is the largest description of GI and psychosocial PRO measures in IBD subjects. There were strong associations between worsened GI-PROMIS domains and worsened QoL, disease activity and psychosocial symptoms. GI-PROMIS holds potential as important PRO measures in IBD and correlates with other accepted indices in this IBD population.