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**Patients in Remission are more Likely to Demonstrate High Patient Activation in a Large Internet-Based Cohort of Patients with Inflammatory Bowel Disease**

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**Background:** High levels of patient activation are achieved when a patient has the necessary knowledge, skills, and confidence to actively and effectively manage their health and care. In other chronic disease populations, higher patient activation has been linked to improved health behaviors and outcomes. Although the concept of patient activation seems highly relevant to IBD and may be a modifiable trait, it has not been well explored. We therefore utilized the Crohn's and Colitis Foundation of America (CCFA) Partners internet cohort to evaluate whether patient activation was associated with disease activity.

**Methods:** We performed a cross-sectional study within the CCFA Partners cohort of patients with a self-reported history of Crohn's Disease (CD) or Ulcerative Colitis (UC). We administered the Patient Activation Measure (PAM, © Insignia Health), a validated, 13 item survey instrument that categorizes patients into 4 stages of activation, to 1486 consecutive cohort participants. We used bivariate analyses and multivariable logistic regression to 1) identify the demographics and clinical characteristics associated with low (stage 1 and 2) or high (stage 3 and 4) patient activation, and 2) evaluate the association between patient activation and clinical remission as measured by a score of < or equal to 2 on the Simple Clinical Colitis Activity Index (SCCAI) for UC or a score of <150 on the Short Crohn's Disease Activity Index (SCDAI) for CD.

**Results:** Among 1486 total participants, 976 (66%) had CD and 510 (34%) had UC. Participants with higher peak education levels, defined as having completed college or higher education, demonstrated higher levels of patient activation [adjusted OR (aOR) 1.56, 95% Confidence Interval (CI) 1.02-2.37]. Similarly, those with a history of more severe disease, as evidenced by prior IBD related surgery, demonstrated higher levels of patient activation (aOR 1.20, 95% CI

0.87-1.66, Table 1). After adjusting for education status, prior surgery, and other confounders, patients with higher patient activation were more likely to be in clinical remission among patients with both CD (aOR 2.94, 95% CI 1.93-4.47) and UC (aOR 2.09, 95% CI 1.16-3.75, Table 2).

**Conclusions:** In this large internet based cohort of patients with IBD, we demonstrated a strong association between patient activation and clinical remission. Patient activation is a relatively novel concept in IBD, and these findings strongly suggest that patient activation may be an important driver of disease outcomes. As this is a modifiable factor, interventions to improve patient activation have the potential improve care and outcomes in this population

Table 1. Odds of high patient activation among participants in CCFA Partners, unadjusted and adjusted analyses

	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Race White Non-White	Reference 0.57 (0.33 - 0.97)	Reference 0.64 (0.35 - 1.16)
Education < 12th Grade 12th Grade Attended College, did not graduate Graduated from College Graduate School	0.34 (0.10 - 1.11) 1.17 (0.61 - 2.25) Reference 1.49 (1.01 - 2.19) 1.46 (0.98 - 2.18)	0.36 (0.10 - 1.23) 1.16 (0.58 - 2.30) Reference 1.56 (1.02 - 2.36) 1.38 (0.90 - 2.11)
Time since Diagnosis <= 10 years >10 years	Reference 1.58 (1.18 - 2.10)	Reference 1.34 (0.97 - 1.85)
Current Smoker	0.44 (0.24 - 0.81)	0.56 (0.28 - 1.09)
History of IBD Related Surgery	1.41 (1.05 - 1.89)	1.20 (0.87 - 1.66)

All variables listed above were included in the final multivariable analysis Table 2. Odds of remission among participants in CCFA Partners, adjusted analyses for Crohn's Disease only and Ulcerative Colitis only populations

	Crohn's Disease Adjusted OR (95% CI)	Ulcerative Colitis Adjusted OR (95% CI)
Patient Activation Low Patient Activation High Patient Activation	. Reference 2.94 (1.93 - 4.47)	. Reference 2.09 (1.16 - 3.75)
Race White Non-White	. Reference 0.55 (0.26 - 1.13)	. Reference 0.46 (0.20 - 1.04)
Education < 12th Grade 12th Grade Attended College, did not graduate Graduated from College Graduate School	. 0.84 (0.12 - 6.10) 0.53 (0.27 - 1.07) Reference . 1.39 (0.90 - 2.15) 1.36 (0.88 - 2.10)	. 0.39 (0.04 - 4.06) 0.58 (0.21 - 1.60) Reference . 1.14 (0.63 - 2.05) 1.93 (1.02 - 3.66)
Time since Diagnosis <= 10 years >10 years	. Reference 1.10 (0.80 - 1.52)	. Reference 1.01 (0.67 - 1.52)
Current Smoker	0.41 (0.18 - 0.96)	0.69 (0.22 - 2.16)
History of IBD Related Surgery	0.68 (0.49 - 0.94)	0.46 (0.20 - 1.07)

All variables listed above were included in the final multivariable analysis