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# Predictive Factors of Inactive Patient Participation in an Inflammatory Bowel Disease Learning Health System: A Longitudinal Cohort Study

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## Lay Summary

Patient participation is crucial to learning health systems that leverage patient data to improve care practices. Age, history of anxiety or depression, and frequency of clinic visits were associated with inactive participation in an inflammatory bowel disease learning health system.

**Key Words:** patient participation, electronic health surveys, inflammatory bowel disease learning health system

## Introduction

Learning health systems that leverage patient data to generate information and improve practices have shown promise in the management of complex chronic diseases such as inflammatory bowel diseases (IBDs).<sup>1</sup> The IBD Qorus Learning Health System collects patient data across the United States via previsit electronic surveys, which capture patients' self-reported disease symptoms and treatment goals. Survey results inform the development of patient-centered care strategies and quality improvement interventions. Previous studies have shown that participation in Qorus resulted in a reduction in healthcare costs, emergency department visits, and opioid use.<sup>1,2</sup>

Nevertheless, longitudinal survey completion could be burdensome to patients. Survey omission poses missed opportunities for shared decision making and the production of representative patient data to inform equitable interventions. This study assesses the predictors of patients' inactive survey participation to inform engagement strategies in Qorus and other IBD care programs that rely on electronic patient survey data.

## Methods

We performed a retrospective cohort study using both electronic health records and previsit survey data from a private community gastrointestinal practice in Rhode Island engaged with Qorus between 2016 and 2021. The practice has maintained active membership in Qorus since 2015. Patients are considered to have participated in Qorus after they enrolled (consented to participate) and submitted their first survey (participated). A total of 244 patients with IBD who participated in Qorus were followed for 2 years after submitting the first previsit survey. Patients received emails that contained links to the previsit surveys on the Qorus online platform 2 weeks before their clinic visit. Survey results were saved and used for discussions during clinic visits.

We defined patient participation as the ratio of eligible surveys to the number of clinic visits. Surveys were only considered eligible if they were submitted within 2 weeks prior to their respective clinic visits. Patients with a ratio below 0.5 were classified as inactive participants, while those

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### Key Messages

#### What is already known?

Learning health systems have shown promise in the management of inflammatory bowel disease.

#### What is new here?

Patients' older age, history of anxiety or depression, and higher number of clinic visits predict inactive participation in an inflammatory bowel disease learning health system.

#### How can this study help patient care?

This study may inform engagement strategies that promote longitudinal patient participation in inflammatory bowel disease learning health systems.

with a ratio  $\geq 0.5$  were classified as active participants. The first survey and its associated clinic visit were excluded from participation score calculation because this survey is usually completed during the enrollment process. For example, if a patient completed 1 additional survey after their first survey, then only the second survey counts for the participation score.

We performed multivariable logistic regression to determine predictive factors for inactive participation. We selected predictor variables after a comprehensive literature review of factors associated with loss of follow-up across different medical specialties.<sup>3,4</sup> We investigated patient demographic information (age, sex, and marital status), IBD subtype, history of depression or anxiety, baseline disease severity, and prior healthcare utilization in our multivariable logistic regression. The history of depression or anxiety was ascertained by clinical notes in the electronic medical records. Prior healthcare utilization included the number of clinic visits. It also included the use of computed tomography (CT) scans, steroids, and IBD-related hospitalization within 6 months before the first survey submission based on electronic medical records. Baseline disease severity was assessed as inactive, mild, moderate, or severe by the physicians.  $P < .05$  was considered statistically significant.

All analyses were conducted using R version 4.2.0 (R Foundation for Statistical Computing). The Lifespan Institutional Review Board approved the study. Each participant consented to participate upon enrollment in Qorus and remained de-identified throughout the analysis.

## Results

Within the study period, 330 patients enrolled in IBD Qorus. Of those, 266 patients enrolled at least 2 years prior to the end of the study. Among these 266 patients, 244 patients submitted their first survey (participated) and were included in the analysis. Of the 244 included patients, 24 had missing baseline disease severity covariate data (considered "unknown").

There were 122 (50%) inactive participants and 122 (50%) active participants. While inactive participants completed a median of 0 (interquartile range [IQR]: 0-1) surveys and 3 (IQR: 1-5) clinic visits, active participants completed a

median of 2 (IQR: 1-3) surveys and 2 (IQR: 2-4) clinic visits. Table 1 compares the characteristics of inactive and active participants.

Multivariable logistic regression revealed that older age, history of anxiety or depression, and higher number of clinic visits were significantly associated with inactive participation (Table 2). The odds ratio (OR) for patients between 35 and 44 years of age was 0.29 (95% confidence interval [CI], 0.10-0.79) compared with those who were 18 to 24 years of age. Similarly, the OR for patients 45 to 54 years of age was 0.24 (95% CI, 0.08-0.68) and above 55 years of age was 0.29 (95% CI, 0.10-0.75). The OR for patients with a history of anxiety or depression was 0.46 (95% CI, 0.26-0.80). The OR for patients with a higher number of clinic visits was 0.88 (95% CI, 0.78-0.97).

Patients' sex, IBD subtype, and baseline disease severity were not associated with inactive participation. Similarly, previous use of CT scans, steroids, and IBD-related hospitalization were not associated with inactive participation.

## Discussion

This study followed a cohort of 244 patients enrolled in the IBD Qorus Learning Health System over 2 years to assess the predictive factors of inactive participation in electronic health surveys. We found that age above 35 years, history of anxiety or depression, and frequent clinic visits were associated with inactive participation. These findings align with previous studies, which found that older individuals were less likely to use digital health technology<sup>5</sup> and that concomitant mental health disorders were associated with reduced healthcare participation.<sup>3</sup> We speculate that patients with more frequent clinic visits experienced participation fatigue, which may explain their increased odds of inactive participation compared with patients with less frequent clinic visits. In addition, these patients may have greater medical needs that take priority over voluntary surveys.

Few studies have analyzed patient participation in gastrointestinal care,<sup>6</sup> and few studies have examined patient electronic survey participation in the context of a learning health system.<sup>7</sup> Given the growth of digital health that was further accelerated by the COVID-19 pandemic, this study could provide preliminary knowledge to help guide strategies that promote continuity of patient care.

The strengths of this study include its 2-year follow-up period, which helps to reflect patients' longitudinal involvement in the learning health system. In addition, the combination of electronic medical records and surveys provides comprehensive patient data. Weaknesses of this study include a single-institution setting that may not reflect the characteristics of all patients who participate in the learning health system. Because this was a retrospective study using data not originally collected for research, it could not assess factors that may predict patient participation such as patients' access to technology, level of education, and attitudes toward the learning health system. Future qualitative studies of patients' motivations for active participation are warranted. In addition, studies may investigate the effects of targeted support for patient subgroups on the level of participation in a learning health system.

**Table 1.** Characteristics of the cohort, inactive, and active participant groups.

	Total (N = 244)	Inactive participants (n = 122)	Active participants (n = 122)
Number of eligible surveys	1 (0-8)	0 (0-5)	2 (1-8)
Number of clinic visits	3 (1-18)	3 (1-18)	2 (1-15)
<b>Age</b>			
18-24 y	50 (20.5)	17 (13.9)	33 (27.0)
25-34 y	53 (21.7)	23 (18.9)	30 (24.6)
35-44 y	51 (20.9)	30 (24.6)	21 (17.2)
45-54 y	36 (14.8)	22 (18.0)	14 (11.5)
≥55 y	54 (22.1)	30 (24.6)	24 (19.7)
<b>Sex</b>			
Female	112 (45.9)	58 (47.5)	54 (44.3)
Male	132 (54.1)	64 (52.5)	68 (55.7)
<b>Marital status</b>			
Union	117 (48.0)	65 (53.3)	52 (42.6)
Nonunion	127 (52.0)	57 (46.7)	70 (57.4)
<b>IBD subtype</b>			
Ulcerative colitis	79 (32.4)	40 (32.8)	39 (32.0)
Crohn's disease	165 (67.6)	82 (67.2)	83 (68.0)
<b>History of depression or anxiety</b>			
Yes	121 (49.6)	72 (59.0)	49 (40.2)
No	123 (50.4)	50 (41.0)	73 (59.8)
<b>Baseline disease severity</b>			
Inactive	126 (51.6)	64 (52.5)	62 (50.8)
Mild	70 (28.7)	35 (28.7)	35 (28.7)
Moderate	24 (9.8)	11 (9.0)	13 (10.7)
Severe	0 (0)	0 (0)	0 (0)
Unknown	24 (9.8)	12 (9.8)	12 (9.8)
<b>6 mo prior IBD-related CT use</b>			
Yes	16 (6.6)	9 (7.4)	7 (5.7)
No	228 (93.4)	113 (92.6)	115 (94.3)
<b>6 mo prior IBD-related ED visit or hospitalization</b>			
Yes	33 (13.5)	17 (13.9)	16 (13.1)
No	211 (86.5)	105 (86.1)	106 (86.9)
<b>Taking steroids at the time of the first survey</b>			
Yes	25 (10.2)	10 (8.2)	15 (12.3)
No	219 (89.8)	113 (92.6)	106 (86.9)

Values are median (range) or n (%).

Abbreviations: CT, computed tomography; ED, emergency department; IBD, inflammatory bowel disease.

## Conclusion

This was a retrospective study that assessed predictors of inactive patient participation in electronic health surveys in an IBD learning health system. We found that age above 35 years, history of anxiety or depression, and frequent clinic visits were associated with inactive participation, while baseline disease severity and prior CT, emergency department, and steroid use were not associated with inactive participation.

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## Conflicts of Interest

C.S.T. has received research grant funding from the American Gastroenterological Association. G.Y.M. has served as a consultant for AbbVie, Arena, Bristol Myers Squibb, Boehringer Ingelheim, Entasis, Medtronic, Nephroceuticals, Oshi, Pfizer, Samsung Bioepis, Takeda, and Techlab; and received research funding from Pfizer and the Crohn's and Colitis Foundation.

**Table 2.** Associations between predictive factors and active participation in the Qorus Learning Health System.

	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	P value for adjusted OR
Number of clinic visits	0.92 (0.83-1.01)	0.88 (0.78-0.97)	.017 <sup>a</sup>
Age			
18-24 y	Ref	Ref	
25-34 y	0.67 (0.30-1.49)	0.59 (0.24-1.41)	.2363
35-44 y	0.36 (0.16-0.80)	0.29 (0.10-0.79)	.0169 <sup>a</sup>
45-54 y	0.33 (0.13-0.79)	0.24 (0.08-0.68)	.0083 <sup>a</sup>
≥55 y	0.41 (0.18-0.90)	0.29 (0.10-0.75)	.0128 <sup>a</sup>
Sex			
Female	0.88 (0.53-1.45)	1.42 (0.80-2.53)	.2358
Male	Ref	Ref	
Marital status			
Union	0.65 (0.39-1.08)	1.03 (0.54-2.01)	.9075
Non-union	Ref	Ref	
Disease diagnosis			
Ulcerative colitis	Ref	Ref	
Crohn's disease	1.04 (0.61-1.78)	1.29 (0.71-2.37)	.4104
History of depression or anxiety			
Yes	0.47 (0.28-0.77)	0.46 (0.26-0.80)	.0064 <sup>a</sup>
No	Ref	Ref	
Baseline disease severity			
Inactive	Ref	Ref	
Mild	1.03 (0.57-1.85)	1.22 (0.63-2.37)	.5602
Moderate	1.22 (0.51-2.98)	1.73 (0.62-4.93)	.2964
Unknown	1.03 (0.43-2.49)	1.41 (0.54-3.76)	.4809
6 mo prior IBD-related CT use			
Yes	1.68 (0.26-2.12)	0.60 (0.16-2.10)	.4214
No	Ref	Ref	
6 mo prior IBD-related ED visit or hospitalization			
Yes	1.37 (0.56-3.48)	1.40 (0.55-3.62)	.4792
No	Ref	Ref	
Taking steroids at the time of the first survey			
Yes	1.76 (0.75-4.35)	2.03 (0.73-5.95)	.1818
No	Ref	Ref	

Abbreviations: CI, confidence interval; CT, computed tomography; ED, emergency department; IBD, inflammatory bowel disease; OR, odds ratio.  
<sup>a</sup>P < .05.

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