

**Table S1. Baseline characteristics reported by the participants by type of diagnosis.**

Questionnaire items	Median (IQR) or N. (%)		P-value <sup>1</sup>
	Crohn's disease	Ulcerative colitis	
Demographic characteristics			
Age	41 (32–51; n = 411)	40 (33–51; n = 345)	0.83 <sup>2</sup>
Gender			
Female	275/427 (64.4)	237/355 (66.8)	0.27
Male	152/427 (35.6)	118/355 (33.2)	
Language			
Italian	72/427 (16.8)	92/355 (25.9)	< 0.001
Finnish	46/427 (10.8)	91/355 (25.6)	
Portuguese	49/427 (11.5)	28/355 (7.9)	
Slovenian	49/427 (11.5)	35/355 (9.9)	
Spanish	61/427 (14.3)	40/355 (11.3)	
Greek	53/427 (12.4)	31/355 (8.7)	
English	37/427 (8.7)	23/355 (6.5)	
German	39/427 (9.1)	7/355 (2.0)	
French	21/427 (4.9)	8/355 (2.2)	
IBD characteristics and treatments			
Disease duration (years)	11 (5–20; n = 427)	4 (1–8; n = 355)	< 0.001 <sup>2</sup>
Self-perceived disease activity			
Inactive	76/425 (17.9)	79/345 (22.9)	0.025
Mildly active	133/425 (31.3)	128/345 (37.1)	
Moderately active	155/425 (36.5)	96/345 (27.8)	
Severely active	48/425 (11.3)	28/345 (8.1)	
Not sure	13/425 (3.0)	14/345 (4.1)	
Self-perceived disease severity since diagnosis			
Mild	86/424 (20.3)	87/344 (25.3)	0.16
Moderate	201/424 (47.4)	159/344 (46.2)	
Severe	121/424 (28.5)	80/344 (23.3)	
Not sure	16/424 (3.8)	18/344 (5.2)	
Intestinal surgery	206/427 (48.2)	24/355 (6.8)	< 0.001
Type of surgery			
Partial colectomy	38/427 (8.9)	3/355 (0.8)	< 0.001

Full colectomy	19/427 (4.4)	10/355 (2.8)	0.26
Small-bowel resection	47/427 (11.0)	1/355 (0.3)	< 0.001
Ileocaecal resection	93/427 (21.8)	1/355 (0.3)	< 0.001
Other	69/427 (16.2)	10/355 (2.8)	< 0.001
Current IBD-related medications			
Antibiotics	28/427 (6.6)	13/355 (3.7)	0.08
Oral aminosalicylate	94/427 (22.0)	224/355 (63.1)	< 0.001
Topical aminosalicylate	8/427 (1.9)	83/355 (23.4)	< 0.001
Topical steroid	9/427 (2.1)	38/355 (10.7)	< 0.001
Systemic steroid	36/427 (8.4)	42/355 (11.8)	0.12
Budesonide	18/427 (4.2)	10/355 (2.8)	0.34
Immunomodulator	141/427 (33.0)	72/355 (20.3)	< 0.001
Anti-TNF	166/427 (38.9)	59/355 (16.6)	< 0.001
Combination of anti-TNF and immunomodulator	50/427 (11.7)	19/355 (5.4)	0.002
Anti-integrin	27/427 (6.3)	24/355 (6.8)	0.88
Tofacitinib	0/427 (0)	6/355 (1.7)	0.009
Ustekinumab	25/427 (5.9)	3/355 (0.8)	< 0.001
None	49/427 (11.5)	27/355 (7.6)	0.07
Other	73/427 (17.1)	62/355 (17.5)	0.92
Duration of current medical therapy (years)			
< 1	134/421 (31.8)	106/344 (30.8)	0.93
1-5	142/421 (33.7)	120/344 (34.9)	
> 25	145/421 (34.5)	118/344 (34.3)	
Concomitant non-IBD drug treatment			
Yes	153/424 (36.1)	129/343 (37.6)	0.71
No	271/424 (63.9)	214/343 (62.4)	

**Footnotes:**

The survey had a hierarchical structure, meaning that only patients who answered to certain items could answer to other following questions. For this reason, the denominator for several questions is different. In some cases, the patient did not answer and this can result in a missing value. We have transparently declared in our tables the denominator we have used to calculate the proportion of patients giving certain answers.

<sup>1</sup>Fisher's exact test

<sup>2</sup>Mann-Whitney U test