The ulcerative colitis narrative Greece survey: patients' and physicians' perspective on quality of life and disease management

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Abstract

Background Using data from the ulcerative colitis (UC) narrative Greece survey, part of a global survey of patients and physicians, we aimed to identify the impact of UC on patients' lives and to compare patients' and gastroenterologists' responses to questions relating to communication during the management of UC in our country.

Methods The survey was conducted online by The Harris Poll, and included 95 patients and 51 gastroenterologists. Eligible were adult UC patients who had seen a gastroenterologist in the past 12 months and had at some time taken a prescription medication (excluding those who had only ever taken 5-aminosalicylates). Patients with mild UC were capped at 20% of total survey respondents to focus the survey on patients with moderate-to-severe disease.

Results The mean time between first experienced symptoms and diagnosis of UC was 0.89 years. Most patients (82%) considered their UC to be in remission, while 98% felt satisfied with their communication with their treating gastroenterologist. However, the disease affected patients' daily life and employment adversely, with 78% reporting their UC to be mentally exhausting. Although nearly 7 in 10 physicians (69%) reported having taken steps to improve their communication skills, many patients (60%) wished they had more time at appointments with their physician, while 44% still felt uncomfortable talking about their sex life and personal relationships.

Conclusions Greek UC patients appear to be satisfied with their physicians and their disease management. Gaps in patient-physician communication relating to quality of life, emotional, and sexual/relationship concerns need to be addressed.

Keywords Ulcerative colitis, quality of life, patient-physician communication

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Introduction

Ulcerative colitis (UC) is a chronic, idiopathic inflammatory bowel disorder characterized by a relapsing/remitting and less often by a chronic active course [1]. Patients with UC most often deal with unpredictable, unpleasant and potentially embarrassing gastrointestinal symptoms, in addition to treatment-related side effects [2]. However, the burden of disease extends far beyond the clinical signs and symptoms from the gastrointestinal tract and/or extraintestinal sites of involvement, since many other aspects of patients' lives are affected [3]. Several studies have shown that patients' employment opportunities, work productivity and social interaction are disturbed [4]. Such issues lead to anxiety and/or depression, which in turn negatively affect patients' quality of life [5]. This is why the recent initiative of the International Organization for the Study of Inflammatory Bowel Disease (IBD), STRIDE-II, has included the absence of disability

and the restoration of quality of life as long-term treatment targets in patients with IBD [6].

Our group reported in 2013 that the health-related social life, emotional status, and work productivity of Greek IBD patients were severely affected and that patients complained of a lack of information regarding their therapy [7]. Although these unmet needs called for immediate action by healthcare providers and society, still today physicians often underestimate the disease burden and associated suffering [8], while they may fail to recognize issues important to patients [9].

The present study aimed to examine the perspectives of Greek patients with UC, using data from the UC Narrative Greek survey. This survey aimed to identify the impact of UC on patients' lives and compare patients' and physicians' responses to questions regarding the management of UC. Understanding gaps in patient–physician communication and acknowledging that bridging these gaps will inevitably improve patients' quality of life and adherence to treatment, we also aimed to compare our findings with those of a similar survey dating back to 2013, during the first period of biologic therapy in Greece.

Materials and methods

The UC Narrative was a global initiative created by Pfizer to engage the UC community to help identify the impact of living with this disease on patients' lives. The UC Narrative Greece survey findings represent a subset of the UC Narrative global survey, developed with input from the Global UC Narrative Advisory Panel. The initiative involved 2 related global surveys, one patient-based, and one physician-based. The survey of Greek patients and gastroenterologists was conducted online by The Harris Poll between June 25 and August 31, 2020. The patient and physician questionnaires can be found in Supplementary Materials 1 and 2, respectively.

Eligible were adult patients with UC who: i) were >18 years of age; ii) resided in Greece; iii) had been diagnosed with UC (confirmed by histological assessment of ileo-colonoscopic biopsies); iv) had visited a gastroenterologist in the past 12 months; v) had at some time taken a prescription medication for their UC (excluding those who had only ever taken 5- aminosalicylates [ASAs]); and vi) provided informed consent to their inclusion in the survey. Patients who had only ever taken 5-ASAs or had undergone a total colectomy were excluded. Patients who had taken corticosteroids in the past (for a period of less than 4 months during the last 12 months) and were on 5-ASAs at the time of the survey were included in the study.

Eligible gastroenterologists were those who: saw ≥10 UC patients each month (of whom ≥10% were taking a biologic); did not mostly practice in an institution for the chronically ill/chronic pain/palliative care; and had a license to practice as a gastroenterologist in Greece. All participating physicians provided informed consent to their inclusion in the survey.

Disease severity in this study was defined using a novel patient-reported medication history. Patients with moderate to severe UC were defined as those who had taken an immunosuppressant or a biologic for their UC at any time, or had taken corticosteroids

for ≥4 months in the last 12 months. Patients with mild UC were defined as those who had never taken a biologic or immunosuppressant and those who had taken corticosteroids for ≤3 of the past 12 months. Patients with mild UC were capped at 20% of total survey respondents to focus the survey on patients with moderate-to-severe UC. This was deemed necessary, since the primary goal of the survey was to characterize the experiences of UC patients believed to be living with moderate-to-severe disease or those who may be living with poorly controlled disease. The choice to focus on these patient types assumed that these groups (vs. those with milder disease) are more likely to be in need of support and resources, which the survey could help better identify. Remission was self-reported by patients and was defined as disease being controlled with few to no symptoms

The surveys were designed to assess: i) patients' symptoms; ii) the impact of UC on mental health and daily life; iii) the impact of the disease on employment and education; iv) communication between patients and physicians; v) knowledge of the disease; and vi) medication preference and satisfaction. The physician questionnaire mirrored the patient questionnaire where applicable. Physicians were asked to base their survey responses on their experiences of treating patients with moderate-to-severe UC, as defined previously. Questions in both patient and physician questionnaires required respondents to provide a numeric response, to select a single option or multiple options from a list, or to indicate their level of agreement with a statement (ranging from "strongly disagree" to "strongly agree").

Statistical analysis

Survey responses were analyzed globally and by country. Descriptive statistics were used to assess patient and physician responses. Analyses were primarily conducted in IBM SPSS. The raw data were analyzed by The Harris Poll. Given the nature of the survey, there was no formal statistical hypothesis or predetermined sample size.

Ethical considerations

The surveys were non-interventional, were not intended to provide clinical data for treatment decisions and were not conducted as a clinical trial for any endpoints; ethics approval was therefore not required. All respondents provided their informed consent and were compensated by Harris Poll on behalf of the sponsor.

Results

Demography

Overall, 95 adults (47% male), with a mean age of 42±13.69 years, participated in the survey. All respondents resided in Greece, 57% were employed full time and 5% part time, 20% were self-employed full time, and 1% part time, 7%

were a stay-at-home spouse or partner, 6% were not employed but looking for work, 2% were retired and 1% were students. As regards their family status, 36% reported that they did not have any children, while the remaining 64% reported being a parent of 1 child (21%), 2 children (33%), 3 children (7%) or 4 or more children (3%). Further information regarding patient demographics can be seen in Fig. 1. The physicians' study sample consisted of 51 gastroenterologists (76% male), with a mean age of 52±10.21 years, of whom 29% worked exclusively in a hospital or a clinic, 12% worked exclusively in a private doctor's office, while the remaining 57% worked both in a hospital/clinic and in a private doctor's office. Most of them (88%) had more than 10-year experience in specialty practice, while 2% had 0-5-year, and 10% had 6-9-year experience in specialty practice.

Table 1 Emotions experienced during an ulcerative colitis flare

I feel more fatigued	74%
I am restless	59%
I feel guilty for missing events	45%
I feel less confident	44%
I feel scared	35%
I feel embarrassed	35%
I feel hopeless	34%
I feel isolated	32%
I am a lot more angry in general	27%
I feel ashamed	20%
I feel lonely	14%
None of these are true for me during a flare	1%

Time to diagnosis and access to care

The mean time between first experienced symptoms and the diagnosis of UC was 0.89 years (interquartile range=2); more specifically, in 58% of patients it was less than 1 year, whereas in 15%, 17%, 3%, 3% and 4% it was 1, 2, 3, 4 and 5 or more years, respectively. Most patients (94%) had direct access to a gastroenterologist, 32% to a nutritionist/dietician, and 20% to a psychiatrist or psychologist.

Symptoms and medications

Most patients (82%) considered their UC to be in remission, whereas the proportion of patients that the treating physicians believed to be in remission was 68%. Despite the medication used, patients still reported symptoms (Fig. 2). Specifically, when they were asked about the number of bathroom visits for any reason other than to urinate (e.g., to pass stool, air, blood, or mucus) on their best day, 17% reported one bathroom visit, 34% reported 2-3 bathroom visits, 40% 4-9 bathroom visits, and 9% ≥10 bathroom visits. Meanwhile, most patients (95%) reported having had at least 1 flare in the past 12 months; more specifically, 15% reported 1 flare, 27% 2 flares, 22% 3 flares, 9% 4 flares, 8% 5 flares, 7% 6-9 flares, and 5% ≥10 flares.

Impact of UC on mental health and daily life

Nearly 4 in 5 patients (78%) found their UC to be mentally exhausting, even among patients with milder disease or those who self-reported to be in remission. More than 2 in 3 UC
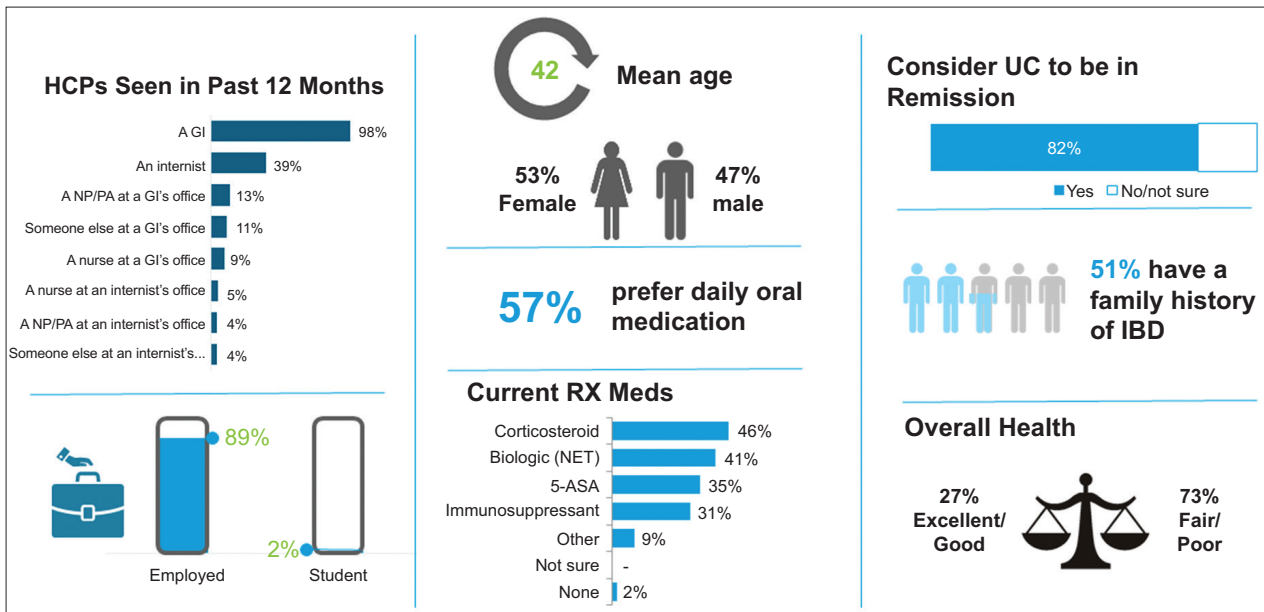

Figure 1 Profile of patients with ulcerative colitis in Greece
HCP, healthcare practitioner; GI, gastroenterologist; NP, nurse practitioner; PA, physician assistant; UC, ulcerative colitis: RX, prescription; 5-ASA, 5-aminosalicylate acid; IBD, inflammatory bowel disease
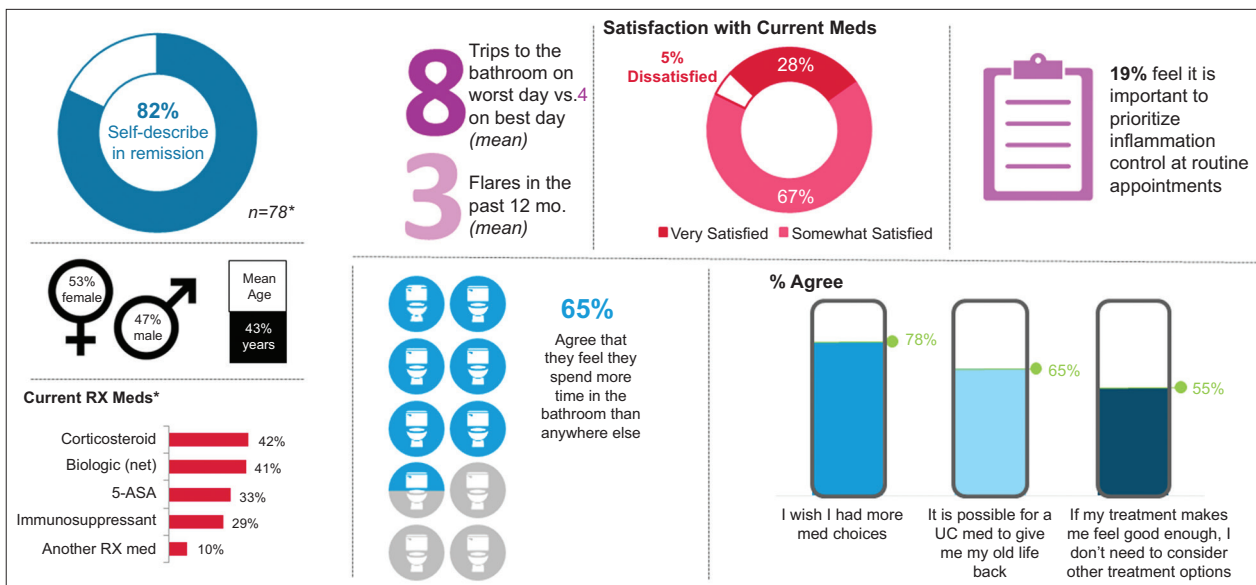
Figure 2 Patients who self-report remission still experience disease symptoms and impacts
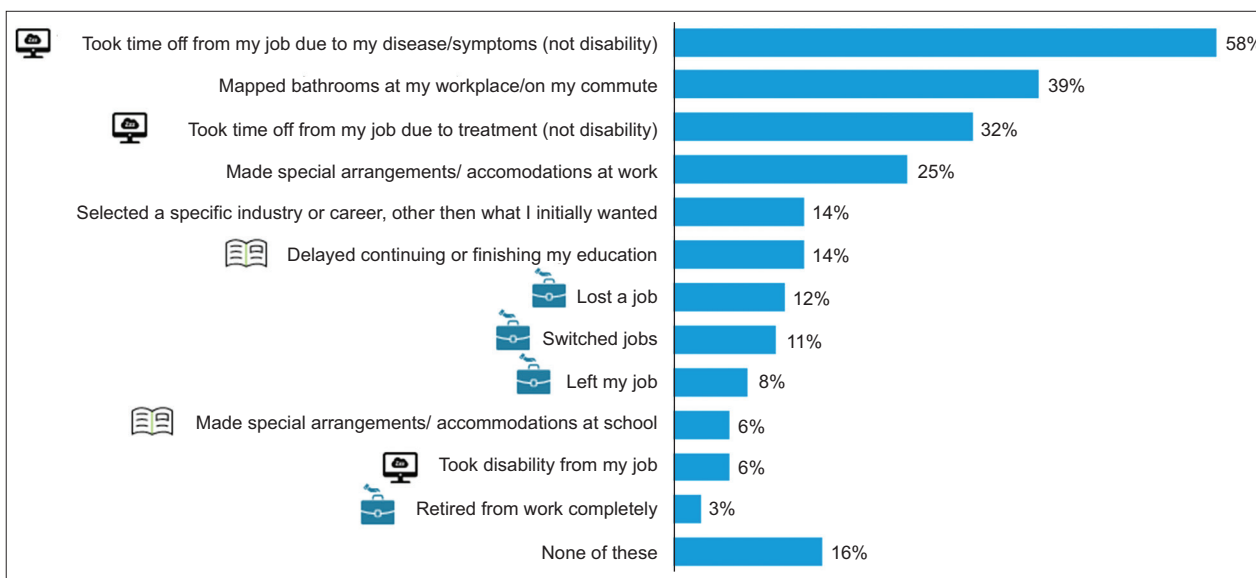*UC, ulcerative colitis; RX, prescription, 5-ASA, 5-aminosalicylate*

Figure 3 Work- and education-related actions as a result of ulcerative colitis

patients (68%) felt that the disease controlled their life, rather than themselves. Patients experienced a variety of emotions during a UC flare, mostly increased fatigue (74%), as can be seen in Table 1. When patients were asked about their top 5 worries due to UC, they mentioned the potential risk of developing cancer (54%), or the need for a colectomy or a stoma in the future (51%), the fear that UC might get worse (47%) or cause other long-term health problems (32%), and the risk of passing on the disease to their children (25%). Patients reported missing a variety of events due to their UC, including their children's events (54%), social events (46%) or travel plans (60%). One third of patients reported specific family impacts due to their UC, such as postponing having children (14%), and ending romantic relationships or avoiding

marriage (14%). Meanwhile, many physicians (51%) felt that the majority of their patients had accepted the fact that having UC meant settling for a reduced quality of life. Furthermore, while physicians did appear aware of patients' top UC-related worries, only 16% of them said discussing cancer risk was a top priority during routine appointments.

Impact of UC on employment and education

Overall, UC had a negative impact on patients' employment (Fig. 3). Four in 5 (81%) patients felt they would be more successful if they did not have UC. Most employed patients (88%) reported having

missed at least 1 day of work because of their disease/symptoms, while 79% had missed work because of treatment or medical appointments. Although most patients (65%) agreed that their employer was understanding, more than one-third (36%) had not reported that they were suffering from UC, for fear of repercussions. Three in 5 patients (61%) said their UC had a negative effect on their confidence at work; however, despite the added difficulties, over three quarters of employed patients (78%) felt their UC had made them better at managing workloads. Physicians appeared to appreciate the negative impact UC has on their patient's employment, since 65% of them agreed that patients would approach their career or education differently if they did not have UC.

Communication between patients and physicians

Most patients (98%) felt satisfied with the patient–physician communication. Patients were most satisfied with discussion of disease control and medications (98% and 96%, respectively), while mental/emotional impacts fell lower on their priority list (80%). Though high satisfaction was reported, the same patients still mentioned areas for improvement related to communication. Many of them (60%) agreed they wished they had more time at appointments with their physician, 57% wished they could talk more about goals with the physician, 44% felt uncomfortable talking to their physician about their sex life and personal relationships, while 30% worried that if they asked too many questions they would be seen as a difficult patient, something that would affect the quality of their care. On the other hand, physicians' perception of patients' satisfaction with their communication about UC tracked below patient-reported satisfaction (84%). Physicians identified a variety of items that would help improve their patient relationships, such as discussion of whether they took their medication exactly as prescribed (55%) and better access to colonoscopies (43%). Nearly 7 in 10 physicians (69%) reported having taken steps to improve their communication skills with their patients. Physicians appeared fairly aligned on what is most important to patients when managing UC, since reducing cancer risk ranked high (71%) and ability to conduct daily activities ranked first (82%) in the list (Fig. 4). Both patients and physicians in Greece (58% and 63%, respectively) agreed that there is need for more discussion about goals for managing or treating UC. Furthermore, both patients and physicians (57% and 51%, respectively) expressed a desire for greater discussion of patients' fears about medical treatments. A significant barrier for greater conversations during scheduled appointments was lack of time, since 36% of patients and 35% of physicians agreed that they rarely had time to raise or respond to all questions and concerns. Furthermore, nearly half of the patients (53%) regretted not saying more during appointments.

Knowledge of disease – patient advocacy groups

Most patients (86%) wished for more information about medications and support when they were first diagnosed. Misconceptions still exist pertaining to inflammation, since 47% of patients stated that if their symptoms were under control there is no active disease or inflammation, 25% were not sure or incorrectly thought that uncontrolled inflammation is not a risk factor for colorectal cancer, while 13% thought that keeping the
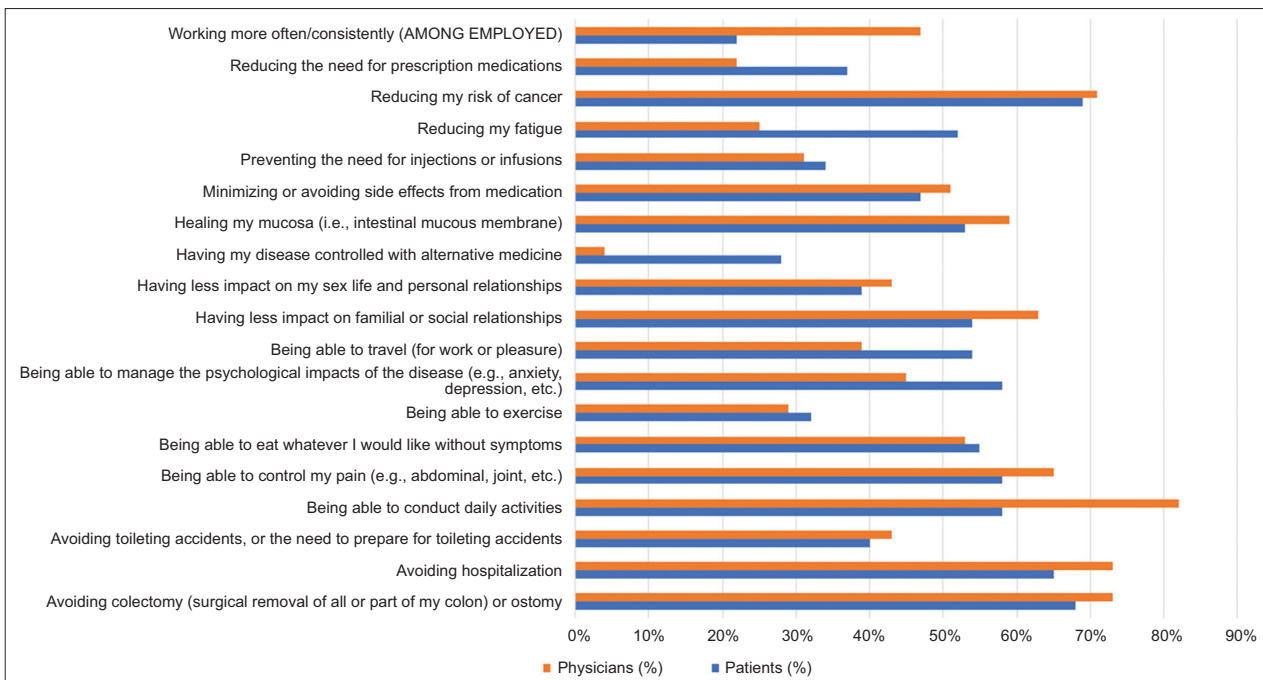

Figure 4 Top priorities in ulcerative colitis management for patients and physicians
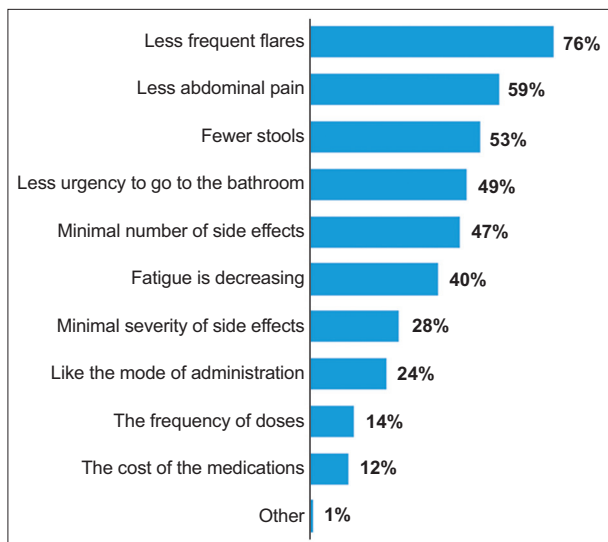Small base site (n<100); results should be interpreted with caution

Figure 5 Reason for satisfaction with current treatment for ulcerative colitis

disease under control does not reduce the risk for long-term complications. More importantly, a third of patients (33%) were not aware that UC may be associated with out-of-gut manifestations, and 25% of physicians did not feel their patients had understood this well. Both patients and physicians agreed on the importance of patients' associations (91% and 86%, respectively); however, 4 in 5 physicians (80%) wished there were resources they could refer their patients to for more information and support. Finally, on average, physicians only reported recommending these groups to a third of their patients and similarly, despite reported importance, less than half of the patients (45%) had interacted with patients' organizations in some way. The top type of information patients would be interested in receiving from a patients' association was how to live better with UC (80%).

Medication preference and satisfaction

Patients' satisfaction with current UC medications appeared to be high (92%); however, the physicians' perspective on what proportion of their patients were satisfied was somewhat lower (69%). Decreased frequency of flares was the top reason for medication satisfaction (76%) (Fig. 5). Half of the patients (51%) wished for earlier discussion of all medication options and physicians wished they had time to do so (61%). Nearly 9 in 10 patients (88%) felt their gastroenterologist was prescribing the very best available medication for their unique experiences; however, 55% of them stated that if the treatment they received made them feel good enough, they did not see a need to consider other treatment options, even if this change might make them feel even better. Nearly 4 in 5 patients (78%) wish they had more medication choices, while daily oral medication was the preferred treatment among most patients (57%) and the physicians agreed (98%). As regards adherence to treatment, a quarter of the patients (25%) hesitated to disclose non-adherence to their physician, while most physicians (94%) believed that

more than half of their patients took their medication exactly as prescribed. More than half of the patients (56%) were not aware of the risks of using steroids over the long term, and 2 in 3 patients currently taking steroids (66%) said they were afraid they would immediately flare if they stopped taking them. About 3 in 4 patients (74%) wished they had moved to biologics sooner, while more than 2 in 5 patients (44%) did not know that it is possible for biologics to exhibit a secondary loss of response. Finally, although most patients (68%) believed that the benefit of biologics outweighs the risks, nearly 1 in 5 patients (18%) currently taking a biologic were not happy with this treatment.

Discussion

The results of this study show encouraging levels of satisfaction among Greek patients with UC, as regards both their perception of being in remission (82%) and their communication with their treating gastroenterologist (98% felt satisfied). Despite these favorable responses, the disease seems to affect patients' daily life and employment adversely, with 78% reporting that they found their UC to be mentally exhausting. Although remission rates seem high, it has to be noted that remission was self-reported by patients and defined as disease being controlled with few to no symptoms. Equally high remission percentage rates have been reported in other published UC Narrative Surveys [9,10]. Furthermore, in the UC NORMAL Survey the majority of patients (58%) indicated that, for them, remission meant living with UC symptoms, so as mentioned in this paper, patients probably had a lower standard for what remission meant for them personally than physicians [11].

In the present study, the mean time between first experienced symptoms and diagnosis of UC was 0.89 months. This is in accordance with previous studies documenting significant delays between first symptoms and diagnosis in IBD in general and UC in particular [12,13]. In the Swiss IBD cohort study, the median diagnostic delay in patients with UC was 4 months [14], while similar findings have also been presented from a recently published Austrian cohort, where the median diagnostic delay in UC was 3 months (1-10 months) [15].

Back in 2013, our group reported that IBD adversely affected patients' daily lives, since most patients (55%) had to cancel their participation in social events and felt depressed or disappointed because of the disease [7]. Similar results appear to apply 8 years later, even though today gastroenterologists have more choices available for treating their patients. Considering that 68% of UC patients in Greece feel that the disease impacts their lives negatively, while at the same time 8 of 10 patients (78%) wish they had more medication choices, there is clearly a treatment gap in current UC management that needs to be seriously addressed. Although 68% of all patients believe that the benefit of biologics outweighs the risks, and 7 of 10 patients currently on biologics wished they had moved to this therapy sooner, adherence is still a key issue that affects treatment success. According to our findings, a quarter of patients hesitate to disclose non-adherence to their physician, which emphasizes the need for better patient–physician communication. Medication

preference is particularly important, and patients' choices should be taken into account when we decide about the best medical therapy for them. Patients do seem to have a clear preference for oral administration (57%) and this is also supported by other studies [16-21], something that should be definitely taken into account if adherence to treatment needs to be increased.

In 2013, the vast majority of Greek IBD patients (88%) reported overwhelming support from their family and friends and appeared to be hesitant to participate in patients' groups. Interestingly, this has not changed over the years, since although 85.1% of patients in the current survey agreed that patients' associations are important for the management of UC, only 69.9% had interacted with a patients' association in any way. Although this emphasizes the still strong supporting role of the Greek family for its suffering members, a vital issue in Greek culture, our findings should nevertheless encourage all physicians to provide information on patients' associations to their patients at an early stage.

Communication is the backbone of chronic disease management, and the present study showed that physicians are fairly aligned on what is most important to patients when managing UC. Previous studies have emphasized the need for symptom control and normalization of quality of life [22,23], and indeed physicians do consider the ability to conduct daily activities as the most desirable treatment goal. It is of interest, though, that patients' most desirable treatment goals are reducing cancer risk and avoiding colectomy. Many studies have reported on the need for better patient–physician communication [24-28], and indeed a significant percentage of Greek gastroenterologists (69%) report having taken steps to improve their communication skills with their patients. Empowering patients through information and support facilitates shared decision-making and a treat-to-target approach, in which physicians and patients are partners [29].

On the other hand, our results also highlight areas where changes can be made to enhance patient–physician interaction. More time should be allocated during scheduled appointments to discuss UC and treatment options. Most physicians tend to focus on treating the disease rather than treating the patient, and as a consequence not all gastroenterologists discussed lifestyle issues with their patients. It is of interest that 44% of the patients surveyed here were not comfortable discussing their sex life and personal relationships with their physician, results similar to those of previous studies [24,30]. These findings do highlight the importance of implementing multidisciplinary teams for better management of UC patients, with the participation of trained psychologists/psychiatrists. Indeed, 20% of our UC patients participating in this survey were already consulting a psychologist/psychiatrist. The participation of an IBD nurse—which unfortunately is not common practice in Greece—can help with management and improve patient relationships. Apart from that, online forums can provide information and support to patients in addition to those provided by the treating physician.

Our study has several strengths and some limitations. This study provides important data on UC patients' most common worries and fears. The questionnaire administered to the patients was detailed, and gathered valuable information about patients' daily quality of life, employment, and mental status. By comparing these results to our previous findings, we had the opportunity to see what changes, if any, our UC patients had

experienced regarding their disease management over the years. Also, for the first time, patients' answers were matched with those given by their physicians, something that adds value to the results. Among the limitations is the fact that the authors were not aware of the criterion on which the original questionnaire was sent out, because the vendor responsible for the execution of the survey classified this information as confidential. Furthermore, voluntary participation creates a response bias and the results from the UC Narrative patient sample survey may therefore not reflect the experiences of the broader UC population. The interpretation of patient survey findings was limited by those patients who self-reported a diagnosis of UC, and by relying upon patients' accurate recall of UC management and their understanding of the survey questions. Furthermore, disease severity was determined by patient-reported medication history, with no clinical assessment to determine disease activity, while an endoscopic and biochemical assessment to determine disease activity was lacking. Finally, the comparison between patients' and physicians' perspectives did not include patients with mild disease, since these patients only made up 20% of the total survey responders.

Summary Box

What is already known:

- Patients with ulcerative colitis (UC) most often deal with unpredictable, unpleasant and potentially embarrassing gastrointestinal symptoms, in addition to treatment-related side effects
- The burden of disease extends far beyond the clinical signs and symptoms, and several studies have shown that patients' employment opportunities, work productivity and social interaction are disturbed, leading to anxiety and/or depression that in turn affect negatively patients' quality of life
- The recent initiative of the International Organization for the Study of Inflammatory Bowel Disease (IBD), the STRIDE-II, has included the absence of disability and the restoration of quality of life as long-term treatment targets in patients with IBD

What the new findings are:

- The results of our study show encouraging levels of satisfaction among Greek UC patients as regards both their perception of being in remission (82%) and their communication with their treating gastroenterologist (98% felt satisfied)
- UC seems to affect patients' daily life and employment adversely, with 78% reporting that they found their disease to be mentally exhausting
- Gaps in patient–physician communication relating to quality of life, emotional, and sexual/relationship concerns should be considered

In conclusion, Greek UC patients appear to be satisfied with their physicians and their disease management. Gaps in patient–physician communication relating to quality of life, emotional, and sexual/relationship concerns should be considered. Allocating more time during scheduled appointments and tackling these challenges can lead to improved patient-to-physician communication and implementation of a shared decision-making approach, thus enhancing patient experience and improving disease outcomes.

Acknowledgment

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Supplementary material

Supplementary material 1

UC Narrative Patient Survey
Greece

SECTION 600: SCREENER

BASE: **ALL RESPONDENTS**
Q264 Thank you for agreeing to take this survey. Our first few questions are for classification purposes and will help us determine which questions to ask you later in the survey. They will also help us properly analyze responses to this survey. As you may already know, we never disclose the identity of any individual. Your answers will always be kept strictly confidential. We report results only for groups of people, not for individuals.

In which country or region do you currently reside?
[STANDARD LIST OF COUNTRIES]
Choice:
[ch14] Australia
[ch33] Brazil
[ch42] Canada
[ch48] China
[ch75] Finland
[ch76] France
[ch85] Germany
[ch89] Greece
[ch116] India
[ch120] Ireland
[ch123] Italy
[ch126] Japan
[ch157] Mexico
[ch196] Russian Federation
[ch214] South Korea
[ch215] Spain
[ch223] Sweden
[ch224] Switzerland
[ch243] United Kingdom
[ch244] United States of America
[ch996] Other country

BASE: **ALL RESPONDENTS**
Q601 What is your sex assigned at birth (what the doctor put on your birth certificate)?
Male
Female

BASE: **ALL RESPONDENTS**
Q271 In what month were you born?
January
February
March
April
May
June
July
August
September
October
November
December

BASE: **ALL RESPONDENTS**
Q270 In what year were you born? Please enter your response as a four-digit number (for example, 1977).
[RANGE: 1900 to CURRENT YEAR-2016]
|__|__|__|__|

BASE: **ALL RESPONDENTS**
Q700 How would you describe your current overall health?
Poor
Fair
Good
Excellent

BASE: **ALL RESPONDENTS**
Q600 Have you personally been told by a doctor that you have any of the following health conditions? Please select all that apply.
[MULTIPLE RESPONSE]
Anxiety
Arthritis
Psoriasis
Celiac disease
Chronic constipation
Crohn's disease
Depression
Diabetes
Eczema
Irritable bowel syndrome (IBS)
Ulcerative colitis **[MUST SELECT TO CONTINUE]**
Chronic anemia
Other inflammatory disease [ANCHOR]
None of these [ANCHOR]

BASE: **HAVE BEEN TOLD THEY HAVE UC**
Q601 To the best of your knowledge do you have a family history of inflammatory bowel disease (IBD), such as Crohn's disease or ulcerative colitis (UC)?
Yes
No
Not sure

BASE: **HAVE BEEN TOLD THEY HAVE UC**
Q605 You indicated that you have been told by a doctor that you have ulcerative colitis. We would now like to ask you a few questions about your experiences with **ulcerative colitis (UC).** Did you have an endoscopic

procedure (i.e., a colonoscopy (a scope) or flexible sigmoidoscopy) in order to confirm your diagnosis of UC?

Throughout the remainder of the survey, when we say UC, please think about your experiences with ulcerative colitis.

Yes
No **[TERMINATE]**
Not sure **[TERMINATE]**

BASE: HAVE BEEN TOLD THEY HAVE UC
Q606 How old were you when you first experienced UC symptoms? If you experienced symptoms before age one, please put 0.

|__|__| years old [RANGE = 1 – AGE AT Q270]

BASE: HAVE BEEN TOLD THEY HAVE UC
Q607 How old were you when you were first diagnosed with UC by a doctor? If you were diagnosed before age one, please put 0.

|__|__| years old [RANGE = 1 – AGE AT Q270]

BASE: HAVE BEEN TOLD THEY HAVE UC
Q608 Have you ever had a colectomy (surgical removal of all or part of your colon)?

Yes **[TERMINATE]**
No

BASE: HAVE BEEN TOLD THEY HAVE UC
Q615 Which health care professionals, if any, do you currently see to manage your UC? When thinking about managing your UC, please include all health care professionals involved in helping you live with and treat the symptoms of your UC, such as managing your medication, treating the inflammation of your colon, etc. Please select all that apply.

[MULTIPLE RESPONSE; RANDOMIZE]
Primary care physician/General practitioner [IF US:/Internist]
　Gastroenterologist
　Rheumatologist
　Dermatologist
　Internist with gastroenterology focus
　Nurse
　Nurse practitioner/Physician's assistant in a gastroenterologist's office
　Nurse practitioner/Physician's assistant in another type of practitioner's office
　Psychiatrist/Psychologist/Therapist
　Nutritionist/Dietician
　Colorectal surgeon
　Other [ANCHOR]
　None [ANCHOR; EXCLUSIVE]

BASE: HAVE BEEN TOLD THEY HAVE UC
Q620 Have you seen a gastroenterologist/internist or another provider at your gastroenterologist's/internist's office or clinic for your UC in the past 12 months? Please select all that apply.

[RANDOMIZE; MULTIPLE RESPONSE]
1. Yes, a gastroenterologist [ANCHOR AT TOP; ROTATE WITH CODE 2]
2. Yes, an internist [ANCHOR AT TOP; ROTATE WITH CODE 1]
3. Yes, a nurse at a gastroenterologist's office
4. Yes, a nurse at an internist's office
5. Yes, a nurse practitioner/physician's assistant at a gastroenterologist's office
6. Yes, a nurse practitioner/physician's assistant at an internist's office
7. Yes, someone else at a gastroenterologist's office [ANCHOR]
8. Yes, someone else at an internist's office [ANCHOR]
9. No [ANCHOR; EXCLUSIVE]

BASE: HAVE BEEN TO GASTRO'S/INTERNIST'S OFFICE IN PAST 12 MO
Q621 In the past 12 months, how many times have you visited your gastroenterologist's/internist's office for your UC? Your best estimate is fine.

|__|__|__| times   [RANGE = 1-200]

BASE: HAVE BEEN TO GASTRO'S/INTERNIST'S OFFICE IN PAST 12 MO
Q622 Is the gastroenterologist's office you have visited in the past 12 months located in an inflammatory bowel disease (IBD) center/clinic?

Yes
No
Not sure

BASE: HAVE BEEN TO GASTRO'S/INTERNIST'S OFFICE IN PAST 12 MO
Q623 Does the gastroenterologist's office you have visited in the past 12 months have inflammatory bowel disease (IBD) specialized nurse(s)?

Yes
No
Not sure

BASE: HAVE BEEN TOLD THEY HAVE UC
Q625 Please indicate all prescription medications you have ever taken for UC.

[MULTIPLE RESPONSE; RANDOMIZE]
Immunosuppressant (e.g., 6-Mercatopurine, Azathioprine, Methotrexate)
Anti-TNF biologic (e.g., Adalimumab (Humira), Golimumab (Simponi), Infliximab (Remicade, Inflectra))
Other biologic (e.g., Vedolizumab (Entyvio))
5-ASA (e.g., Salofalk, Pentasa, Asacol, Mezavant, Asalazine, Cronezil, Mesalazine)
Corticosteroid (e.g., Prezolon, Medrol, Budecol, Budenofalk)
Another prescription medication for UC [ANCHOR]
Not sure [ANCHOR; EXCLUSIVE] **[TERMINATE]**
I have never taken any prescription medications for my UC. [ANCHOR; EXCLUSIVE] **[TERMINATE]**

[TERMINATE IF ONLY 5-ASA IS SELECTED]

BASE: HAVE EVER TAKEN A PRESCRIPTION DRUG
Q630   Please indicate all prescription medications you are currently taking for UC.
[SHOW ONLY MEDICATIONS SELECTED AT Q625 IN SAME ORDER]
Another prescription medication for UC [ANCHOR]
   7. Not sure [ANCHOR; EXCLUSIVE]
   8. I am not currently taking any prescription medications for my UC. [ANCHOR; EXCLUSIVE]

BASE: HAVE EVER TAKEN CORTICOSTEROID TREATMENT
Q635   You indicated that you have taken a corticosteroid for your UC. In the **past 12 months**, for approximately how many months have you taken **corticosteroids** for your UC?
   |__|__| MONTHS   [RANGE: 0-12]

[IF HAVE EVER TAKEN 5-ASA (BUT NOT IMMUNOSUPPRESSANT OR BIOLOGIC) MUST ALSO HAVE TAKEN STEROIDS FOR THEIR UC IN THE PAST 12 MONTHS. MILD PATIENTS=1-3 MONTHS OF STEROIDS IN THE PAST 12 MONTHS; MODERATE TO SEVERE PATIENTS 4+ MONTHS]

BASE: CURRENTLY TAKING BIOLOGIC TREATMENT
Q636   You indicated that you have taken a biologic for your UC. Is the healthcare provider who prescribes your biologic treatment the provider who is mostly responsible for managing your UC?
   1. Yes
   2. No
   3. Not sure

BASE: HAVE BEEN TOLD THEY HAVE UC
Q640 We will be asking you some questions about you and your health, in order to provide the basis of our research. All your responses will remain completely confidential and the research adheres to the Data Protection Act, Market Research Society, Association of the British Pharmaceutical Industry, and international code of marketing and social research practice.

We are not attempting to promote anything to you or to influence you. You have the right to withdraw from the survey at any time while completing the survey.

This survey is being conducted by an independent market research agency, on behalf of a pharmaceutical company, and is for market research purposes only. The pharmaceutical company sponsoring the research is not a recipient of your personal data and, thus, did not have and shall not have any access to your personal data. The pharmaceutical company sponsoring the research will only receive anonymized results which will not be used to support measures or decisions regarding you.

We are also being asked to pass on to our clients the details of side effects or product issues that are mentioned during the course of market research interviews and surveys. Although this is an on-line market research survey and what you say will, of course, be treated in confidence, should you raise a side effect or product issue with certain medications, we will need to report this even if it has already been reported by you directly to your physician or the regulatory authorities. In this situation, the sponsoring pharmaceutical company will only use your data to comply with its own safety legal duties. In such a situation you will be asked whether or not you are willing to waive the confidentiality given to you under the Market Research Codes of Conduct specifically in relation to that side effect or product issue.

Everything else you say during the course of the survey will continue to remain confidential, and you will still have the option to remain anonymous if you so wish.

Are you willing to proceed with the survey on this basis?
Yes
No **[TERMINATE]**

Qualified Respondents will be…
- Resident of country of focus
- Age 18+ (Q280/18+)
- Diagnosed with UC (Q600/12)
- Managed by a gastroenterologist and have been to their GI's office in the last 12 months (Q620=1-4)
- Have had a colonoscopy or flexible sigmoidoscopy to confirm their diagnosis (Q610=1)
- Have ever taken any prescription medication for their UC (Q625=1-6) except for only EVER taken 5-ASA (Q625=4)
- Agree to AE statement (Q640/1)
- Have not had a colectomy (Q608/1)

The treatment question (Q625) will also be used to define severity in this research. We are currently defining respondents as follows:
- Mild: Have ever taken 5-ASA and steroids (Q625/4 & 5) and have been on steroids for 1-3 months within the past 12 months(Q635/1-3) Not to exceed 20% of total sample in each country
- Moderate to Severe: Have ever taken Immunosuppressant or Biologic (Q625/1 or 2 or 3) **or** have ever taken 5-ASA and steroids (Q625/4 & 5) and have been on steroids for greater than 3 months within the past 12 months (Q635/4+)

Survey Begins Here

BASE: ALL RESPONDENTS
Q398   Next, we have a few employment and economic questions.

Q399
   Yes
   No

   Are you employed full time for pay with an organization or company?

Are you employed part time for pay with an organization or company?

Are you self-employed full time?

Are you self-employed part time?

BASE: NOT AT ALL EMPLOYED
Q402 Which of the following best describes your current situation?
Looking for work
Not looking for work
Unable to work due to a disability or illness

BASE: ASK SEQUENTIAL EMPLOYMENT
Q404 Do any of the following describe you? Please select all that apply.
[MULTIPLE RESPONSE]
Retired
A student
A stay-at-home spouse or partner
None of these   E

BASE: ALL RESPONDENTS
Q410 Which one of the following best describes your employment status?
[ONLY SHOW ITEMS SELECTED AT Q398-Q404]
Employed full time
Employed part time
Self-employed full time

15. Self-employed part time
Not employed, but looking for work
Not employed and not looking for work
Not employed, unable to work due to a disability or illness
Retired
Student
Stay-at-home spouse or partner

BASE: ALL RESPONDENTS
Q1305 How many children are you the parent or guardian of?
|_|_| children [RANGE 0-15]

SECTION 700: CURRENT UC EXPERIENCE

[PN: SHOW Q705 AND Q710 ON THE SAME PAGE]
BASE: ALL QUALIFIED RESPONDENTS
Q705 How many times do you go to the bathroom for any reason, including to pass stool, air, or mucus, on your **best day**? Please think of a 24-hour period.
Please do not include trips to the bathroom only to urinate.
Your best estimate is fine.
[RANGE: 0 – 100]
|__|__|__|times

BASE: ALL QUALIFIED RESPONDENTS
Q710 How many times do you go to the bathroom for any reason, including to pass stool, air, or mucus, on your **worst** day? Please think of a 24-hour period.

Please do not include trips to the bathroom only to urinate.
Your best estimate is fine.
[RANGE: 0 – 100]
|__|__|__| times

BASE: ALL QUALIFIED RESPONDENTS
Q715 What is important to you in managing your UC? Please select all that apply. [**Q705 in UC HCP Survey**]
[MULTIPLE RESPONSE; RANDOMIZE]
Be able to conduct daily activities
Be able to exercise
Have my disease controlled with alternative medicine
Prevent the need for injections or infusions
Reduce my risk of cancer
Reduce my fatigue
Work more often/consistently [EMPLOYEES ONLY]
Attend school more often/consistently [STUDENTS ONLY]
Avoid colectomy (surgical removal of all or part of your colon) or ostomy
Have less impact on familial or social relationships
Be able to eat whatever I would like without symptoms
Reduced the need for prescription medications
Avoid hospitalization
Be able to manage the psychological impacts of the disease (e.g., anxiety, depression, etc.)
Have less impact on sex life and personal relationships
Avoid toileting accidents, or the need to prepare for toileting accidents
Heal my mucosa (i.e., intestinal mucous membrane)
Be able to control my pain (e.g., abdominal, joint, etc.)
Be able to travel (for work or pleasure)
Minimizing or avoiding side effects from medication
96. Other   [ANCHOR]
97. Nothing is important to me in managing my UC [ANCHOR; EXCLUSIVE]

BASE: ALL QUALIFIED RESPONDENTS
Q720 In general when thinking about managing your UC, which of the following, if any, are your top 3 worries because of your UC? Please select up to three.
[ALLOW UP TO THREE; RANDOMIZE]
1. That my UC might get worse
2. That my UC might cause other health problems
3. About side effects I may experience from my prescription UC medication(s)
4. That I will not be able to get access to all available medications [HOLD WITH CODE 13]
5. How my UC impacts my personal relationships
6. How my UC impacts my career/education
7. The potential of needing a colectomy or ostomy in the future
8. The potential of passing UC on to my [IF Q1305=0: future] children
9. The potential risk for developing cancer
10. That I may not be able to travel (for work or pleasure)
11. Other [ANCHOR]

12. None – I do not worry about anything because of my UC. [ANCHOR; EXCLUSIVE]
13. That I will not be able to afford medications [HOLD WITH CODE 4]

BASE: **ALL QUALIFIED RESPONDENTS**
Q725 How much do you agree or disagree with each of the following statements about the overall impact of UC on your life?

Q726
Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

[RANDOMIZE]
I often feel like I spend more time in the bathroom than anywhere else
I feel like I would be a more successful person if I did not have UC
I worry I will pass my UC to my [future] children
UC has made me more appreciative of the important things in life
UC has made me more resilient
I feel comfortable discussing my health issues with my family/friends
UC is mentally exhausting
I feel that UC controls my life, rather than me controlling the disease

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SECTION 800: EVERYDAY LIVING

BASE: **ALL QUALIFIED RESPONDENTS**
Q805 Which of the following emotions, if any, do you typically experience during a UC flare? Please select all that apply.
[MULTIPLE RESPONSE; RANDOMIZE]
I am a lot more angry in general
I feel guilty for missing events
I feel lonely
I feel less confident
I am restless
I feel scared
I feel hopeless
I feel ashamed
I feel more fatigued
I feel isolated
I feel embarrassed
None of these are true for me during a flare [ANCHOR; EXCLUSIVE]

BASE: **ALL QUALIFIED RESPONDENTS**
Q816 Do you currently consider your UC to be in remission?
When we say remission we mean that your disease is controlled with few to no symptoms.
Yes
No

BASE: **ALL QUALIFIED RESPONDENTS**
Q810 How many separate UC flares have you had in the past 12 months? If you are not sure, please provide your best estimate.

When we say flare we mean a period of time where you experience a dramatic increase in symptoms that is different than what you typically experience.
[RANGE: 0-100]
|__|__| flares in the past 12 months

BASE: **HAVE HAD FLARE IN PAST 12 MONTHS**
Q815 Thinking of your most recent UC flare, how long did the flare last? If you are not sure, please provide your best estimate.
Less than one week
7-14 Days
15-30 Days
1- 2 Months
3 months or greater

SECTION 900: SOCIAL IMPACT OF UC

BASE: **ALL QUALIFIED RESPONDENTS**
Q900 In the past 12 months, about how many of the following events, if any, have you missed due to your UC? Your best estimate is fine.
[RANDOMIZE; BUT KEEP ITEMS 2-3 AND 4-5 TOGETHER]
[RANGE: 0-200]
My child's events (e.g., parent-teacher conferences, sporting events, plays, etc.) [HAVE CHILDREN ONLY] |_|_|_|
Days of work due to disease/symptoms [EMPLOYED ONLY] |_|_|_|
Days of work due to treatment or medical appointments (e.g., infusion appointments) [EMPLOYED ONLY] |_|_|_|
Days of school due to disease/symptoms [STUDENTS ONLY] |_|_|_|
Days of school due to treatment (e.g., infusion appointments) [STUDENTS ONLY] |_|_|_|
Social events (e.g., weddings, parties, bat/bar mitzvah, dinner with friends, movies, etc.) |_|_|_|
Travel plans (work or pleasure) |_|_|_|

BASE: **ALL QUALIFIED RESPONDENTS**
Q905 Have you done any of the following as a result of your UC? Please select all that apply.
[MULTIPLE RESPONSE; RANDOMIZE]
Left a job
Took disability from my job
Took time off from my job due to my disease/symptoms (not disability) [HOLD BELOW CODE 2]
Took time off from my job due to treatment (e.g., infusion appointments) (not disability) [HOLD BELOW CODE 3]
Retired from work completely
Switched jobs
Lost a job
Selected a specific industry or career, other than what I initially wanted
Made special arrangements/accommodations at work
Delayed continuing or finishing my education
Made special arrangements/accommodations at school

Mapped bathrooms at my workplace/on my commute
97.   None of these   [ANCHOR; EXCLUSIVE]

BASE: ALL QUALIFIED RESPONDENTS
Q910   Have you done any of the following as a result of your UC? Please select all that apply.
[MULTIPLE RESPONSE; RANDOMIZE]
Postponed having children
Decided not to have children/not to have any more children
Postponed, ended, or avoided marriage/romantic relationships
Decided to adopt children
Stopped treatment in order to start a family
97.   None of these   [ANCHOR; EXCLUSIVE]

BASE: EMPLOYED RESPONDENTS
Q915   How much do you agree or disagree with each of the following statements about the impact of UC on work?
Q916
Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

[RANDOMIZE]
    My UC has had a negative effect on my confidence at work
    I am too tired because of my UC to excel in my workplace
    I feel comfortable discussing my health issues in my workplace
    My employer is very understanding of my condition
    I am in too much pain or distracted by the daily needs of my disease to focus on my work
    I have not told my employer about my UC because I fear the repercussions
    Managing my UC has made me better at managing my workload

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SECTION   1000:   RELATIONSHIP   AND COMMUNICATION WITH GASTRO

BASE: ALL QUALIFIED RESPONDENTS (Q99/1)
Q1000   Have you ever…? Please select all that apply.
    [MULTIPLE RESPONSE; RANDOMIZE BUT KEEP 1-2 TOGETHER]
Participated in a support group that meets in-person
    Participated in a support group online (e.g., social media, chat rooms, formal support groups, etc.)
    Participated in a peer mentoring program
    Reached out to a patient association or organization (i.e., organizations that provide information and support to, and lobby on behalf of, patients and their families, such as [IF US, INSERT: the Crohn's Colitis Foundation)
    Relied on information from a patient association or organization or support group to help you make choices about treatment and disease management
    Participated in education program about my UC

Been referred to a patient association or organization by my gastroenterologist
None of these   ANCHOR; E

BASE: INTERACTED WITH PATIENT ASSOCIATION (Q1000/4, 5, 7)
Q1001   How much do you agree or disagree with the following statement?
I wish I knew about patient associations or organizations earlier.
Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

BASE: ALL QUALIFIED RESPONDENTS (Q99/1)
Q1002   What information, if any, would you be interested in receiving from a patient association or organization? Please select all that apply.
[MULTIPLE RESPONSE; RANDOMIZE]
Treatment options
Affordability of treatment, including ways to receive financial assistance [US AND CANADA ONLY]
Research initiatives
Clinical trials
How to live better with UC
How to talk to my spouse/partner about my UC
How to talk to my gastroenterologist about my UC
How to prepare for visits with my gastroenterologist
How to know if my medications are working
Other
None, I am not interested in receiving information from a patient association or organization

BASE: PATIENTS CURRENTLY TAKING BIOLOGICS AND WHO SEE MULTIPLE HCP'S FOR THEIR UC
Q1047   Earlier, you mentioned that you currently see multiple healthcare providers to manage your UC. Who do you primarily communicate with about each of the following aspects of your UC?
Q1048
    1. The healthcare provider who prescribes your biologic treatment
    2. Another healthcare provider
    3. Not applicable

[RANDOMIZE]
    1. Emotional impacts
    2. Symptoms
    3. Side effects of treatment
    4. Treatment
    5. Your quality of life

BASE: ALL QUALIFIED RESPONDENTS
Q1049   As a reminder, for the remainder of the survey, please continue to think about the gastroenterologist mostly responsible for managing your UC.

BASE: ALL QUALIFIED RESPONDENTS (Q99/1)

Q1010   Have you set goals for managing your UC with your gastroenterologist?

When we say goals, please think of what is important to you in managing your UC.

  Yes
  No

BASE: ALL QUALIFIED RESPONDENTS

Q1015   How satisfied are you with the communication you have with your gastroenterologist regarding your UC? [**Q1010 in UC HCP Survey**]

  Very dissatisfied
  Somewhat dissatisfied
  Somewhat satisfied
  Very satisfied

BASE: ALL QUALIFIED RESPONDENTS

Q1020   How satisfied are you with each of the following aspects for how you are managing your UC with your gastroenterologist?

Q1021
  Very dissatisfied
  Somewhat dissatisfied
  Somewhat satisfied
  Very satisfied

[MULTIPLE RESPONSE; RANDOMIZE]

  Discussion of how my current medication may help reach my long-term treatment goals
  Discussion of how my current medication may help reach my day-to-day goals (e.g., go out with friends)
  Discussion of all my prescription medication options, including benefits and side effects
  Discussion of the possibility that my disease can be controlled with few to no symptoms
  Information about upcoming procedures (e.g., day-of schedule, recovery time, any long term side effects, etc.)
  Expectations set around my medication regimen (e.g., how to know if it is working, signs a medication change is necessary, etc.)
  Willingness to discuss alternative therapies (e.g., acupuncture, natural remedies, etc.) despite lack of medical evidence to support efficacy
  Discussion of mental/emotional health impacts of UC
  Expectations set around the long-term realities of living with a chronic and unpredictable disease
  Discussion of symptoms experienced
  Discussion of how treatment modality (i.e., injection, infusion, oral) impacts my quality of life
  Discussion of how I can get more support and information on my condition

BASE: ALL QUALIFIED RESPONDENTS

Q1025   How well do you feel that your gastroenterologist has explained each of the following aspects of managing your UC to you?

Q1026
  Has explained very well
  Has explained somewhat well

  Could explain somewhat better
  Could explain much better

[MULTIPLE RESPONSE; RANDOMIZE, BUT ROTATE 1-2, 3-4 TOGETHER]

  Lifestyle changes (e.g., diet, exercise)
  My current UC status/whether my UC has become better or worse
  Potential risk factors for cancer
  The benefits and risks of biologics on in the disease
  How inflammation relates to my UC
  The importance of getting my inflammation under control, regardless of current symptoms
  What will happen if my UC treatment fails
  The hereditary nature of UC
  The importance of keeping up to date on health maintenance (e.g., vaccinations, examinations, colon cancer surveillance, etc.)
  How to access information and support from patient associations or organizations

BASE: ALL QUALIFIED RESPONDENTS

Q1030   Which of the following topics related to your UC, if any, do you feel are the most important to prioritize during a routine appointment with your gastroenterologist? Please select up to three. [**Q1015 in UC HCP Survey**]

[SELECT UP TO THREE; RANDOMIZE]

  The emotional impacts of UC [HOLD WITH CODE 3]
  The physical impacts of UC [HOLD WITH CODE 2]
  The impacts of UC on sex life and personal relationships
  How to control inflammation
  What to expect next from my UC treatment, including possible changes in my treatment
  New medications that are available for UC
  Side effects of current treatment
  Symptoms/problems experienced since my last visit
  What to expect from my UC long-term
  If I could get cancer
  My ability to afford my medications [US ONLY]
  My ability to manage my fatigue
  My ability to manage my symptoms
  Where to go for additional information and support
  Other [ANCHOR]
  None [ANCHOR; EXCLUSIVE]

BASE: ALL QUALIFIED RESPONDENTS

Q1035   With respect to your communication with the gastroenterologist mostly responsible for managing your UC, how much do you agree or disagree with each of the following statements?

Q1036
  Strongly disagree
  Somewhat disagree
  Somewhat agree
  Strongly agree
  I often regret not telling my gastroenterologist more during my visits.
  I wish my gastroenterologist had discussed all available treatment options earlier, so I had a better idea of my choices. [**Q1000 in UC HCP Survey**]

My gastroenterologist rarely has time to address all of my questions and concerns. [Q1000 in UC HCP Survey]

I wish my gastroenterologist and I talked more about my goals for managing my UC. [Q725 in UC HCP Survey]

I feel comfortable raising concerns and fears with my gastroenterologist. [Q1000 in UC HCP Survey]

I don't feel comfortable talking to my gastroenterologist about emotional concerns [Q1000 in UC HCP Survey]

I don't feel comfortable talking to my gastroenterologist about sex life and personal relationship concerns [Q1000 in UC HCP Survey]

I wish my gastroenterologist and I talked more about my fears of medical treatments. [Q725 in UC HCP Survey]

I am hesitant to tell my gastroenterologist if I don't take my medication exactly as prescribed

I am honest with my gastroenterologist when discussing my experiences with UC [Q725 in UC HCP Survey]

I wish I had more time at appointments with my gastroenterologist [Q725 in UC HCP Survey]

BASE: ALL QUALIFIED RESPONDENTS
Q1040   Which of the following, if any, do you wish your gastroenterologist better understood about your experiences living with UC? Please select all that apply.

[MULTIPLE RESPONSE; RANDOMIZE]

How it affects my mental health
How much I rely on him/her to help me with my UC
The inconvenience of my medications
The stress it causes me and my loved ones
That I would like to manage my UC with my diet
How my disease affects my relationships
How much UC impacts my quality of life
How difficult it is for me to keep a job
How difficult it is for me to stay in school
The importance of not becoming dependent on pain medications
The importance of not becoming dependent on steroids
How exhausted I am
The abdominal pain I experience
How difficult it is for me to afford my medications [SUPPRESS IN EUROPE]
That I would like to talk to others who have UC
That I would like more information about UC and support
How my disease affects my sex life
Other [ANCHOR]
None [ANCHOR; EXCLUSIVE]

BASE: ALL QUALIFIED RESPONDENTS
Q104   With respect to your communication with the gastroenterologist mostly responsible for managing your UC, how much do you agree or disagree with each of the following statements?
Q1046
Strongly disagree
Somewhat disagree

Somewhat agree
Strongly agree

[RANDOMIZE]

When I leave an appointment with my gastroenterologist, I know exactly how to follow his/her treatment recommendations

I worry that, if I ask too many questions, my gastroenterologist will see me as a difficult patient and it will affect the quality of care I receive

I feel that my gastroenterologist is prescribing the very best available medication for my unique set of symptoms and lifestyle issues

Other healthcare providers in my gastroenterologist's office (e.g., nurses, physician assistants, etc.) play a strong role in educating me on treatments and lifestyle adjustments

My gastroenterologist and I work together to make decisions about my UC treatment plan

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SECTION 1100: TREATMENT ATTITUDES AND EXPERIENCES

BASE: ALL qualified RESPONDENTS
Q1100   How many times, if any, have you been hospitalized for your UC in the past 12 months?
When thinking of hospitalizations please think of all times you have been to the hospital, including trips to the emergency room, being admitted to the hospital, etc.
[MANDATORY OPEN END NUMERIC]
|_|_|_| times in the past 12 months [RANGE 0-365]

BASE: ALL QUALIFIED RESPONDENTS
Q1105   How satisfied are you with your current UC medications? [Q1100 in UC HCP Survey]
Very dissatisfied
Somewhat dissatisfied
Somewhat satisfied
Very satisfied

BASE: SATISFIED WITH CURRENT UC TREATMENT
Q1110   You mentioned you are satisfied with your UC medications, for which of the following reasons are you satisfied? Please select all that apply.
Please think of all medications you are taking for your UC.
[MULTIPLE RESPONSE; RANDOMIZE]
The minimal number of side effects [HOLD WITH CODE 2]
The minimal severity of side effects [HOLD WITH CODE 1]
I have fewer stools
I have less frequent flares
The frequency of doses
I experience less abdominal pain
The cost of the medications
Fatigue is decreasing
I like the mode of administration (i.e., injection, infusion, oral)
I experience less urgency to go to the bathroom
Other [ANCHOR]

BASE: NOT SATISFIED WITH CURRENT UC TREATMENT

Q1115 You mentioned you are not satisfied with your UC medications, for which of the following reasons are you not satisfied? Please select all that apply.

[MULTIPLE RESPONSE; RANDOMIZE]

The number of side effects [HOLD WITH CODE 2]
The severity of side effects [HOLD WITH CODE 1]
I have frequent stools
I still have frequent flares
The frequency of doses
I experience more abdominal pain
The cost of the medications
Fatigue is increasing
I do not like the mode of administration (i.e., injection, infusion, oral)
I experience more urgency to go to the bathroom
Other [ANCHOR]

BASE: ALL QUALIFIED RESPONDENTS

Q1120 How much do you agree or disagree with each of the following statements?

Q1121

Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

[RANDOMIZE]

I wish I had more medication choices to treat my UC
I wish I had moved to biologics sooner than I did [CURRENTLY ON BIOLOGICS ONLY] **[Q1000 in UC HCP Survey]**
I am not happy with biologics [CURRENTLY ON BIOLOGICS ONLY]
I believe the benefit of biologics (medication taken through injection or infusion) outweighs the risks (e.g., side effects)
If my treatment makes me feel good enough, I don't see a need to consider other treatment options, even if they might make me feel even better
It is possible for a UC medication to give me back my old life (i.e., before I was diagnosed with UC)
I am afraid if I go off steroids, I will immediately have a UC flare [CURRENTLY ON STERIODS ONLY]
I wish I knew more about all the available medications for UC when I was first diagnosed
I wish I knew where to find information and support when I was first diagnosed with UC
Patient associations or organizations are important to the management of my UC **[Q1000 in UC HCP Survey]**

BASE: ALL QUALIFIED RESPONDENTS

Q1125 Which of the following methods of medication administration would you prefer, assuming they were all equally effective? Please only select one.

[SINGLE RESPONSE; RANDOMIZE]

Oral

Injection in medical facility [HOLD WITH CODE 3]
Self-injection [HOLD WITH CODE 2]
Infusion
No preference [ANCHOR]

BASE: ALL QUALIFIED RESPONDENTS

Q1130 As far as you know, are the following statements about UC treatment true or false, or are you not at all sure? **[Q805 in UC HCP Survey]. If you are interested, we can provide you with the correct answers at the end of the survey.**

Q1131

True
False
Not sure

[RANDOMIZE]

If my UC symptoms are under control there is not active disease or inflammation [FALSE]
It is important to keep my disease under control to reduce long-term complications [TRUE]
Uncontrolled inflammation is a risk factor for colorectal cancer [TRUE]
UC may be associated with other conditions outside of my colon [TRUE]
It is okay to stop taking UC medications once you feel better [FALSE]
It is okay to use steroids as a long term maintenance medication [FALSE]
It is possible for your body to stop responding to biologics, causing the medication to no longer work [TRUE]

SECTION 1200: FEELINGS TOWARDS CHANGES IN MEDICATION REGIMEN

BASE: ALL QUALIFIED RESPONDENTS

Q1205 When thinking about your UC medication(s), what are the top three indicators that it is time to consider changing or adding medications? Please select up to three. **[Q1200 in UC HCP Survey]**

[SELECT UP TO THREE; RANDOMIZE]

Having continued symptoms
Having to adjust the dose multiple times
Being unable to do the things I want to do
Having continued flares
Making additional visits to my gastroenterologist or other health care professional
Having to stop taking a medication because I cannot tolerate the side effects
Inability to go to work consistently [HOLD WITH CODE 10]
Inability to go to school consistently [HOLD WITH CODE 9]
Needing to go to the hospital or emergency room unexpectedly
Frequently needing to call my gastroenterologist's office to express concerns or ask questions
My joints start to bother me
The cost of medications/changes in affordability
Changes in availability of medications

Experienced increased urgency and frequency of stools

Unable to tolerate the mode of administration (i.e., oral, injectable, infusion)

Missing too much work or school to get my medicine

Current medicine is too inconvenient

Hearing from someone else about a different medication option

Desire to have children

96. Other [ANCHOR]

97. None [ANCHOR, EXCLUSIVE]

BASE: GI HAS RECOMMENDED CHANGE IN MED REGIMEN (Q1200/1-3)

Q1220 For which of the following reasons, if any, have you been reluctant when your gastroenterologist has recommended or made a change in your medication regimen? Please select all that apply. **[Q1210 in UC HCP Survey]**

[MULTIPLE RESPONSE; RANDOMIZE]

I was worried about the side effects from the new medication

I was afraid that the new medication would not be any better

I could not afford the medications my gastroenterologist recommended

I didn't like the way the new treatment would be administered (e.g., infusion vs. injection vs. oral medication, etc.)

I thought my current medication was treating my UC well enough

My insurance makes it difficult to change medications

I was afraid of the long-term risks

I was afraid of the possibility of experiencing fertility issues in the future

I did not understand why they were recommending the change

The change was mandated by my health care system

I was worried about getting and managing pregnancy

96. Some other reason [ANCHOR]

97. I have never felt reluctant when my gastroenterologist has recommended a change in medication [ANCHOR; EXCLUSIVE]

ANSWERS TO TRUE/FALSE QUESTIONS

QXXXX Earlier in this survey, you responded to several true/false questions. Please see below for the correct answers to these questions.

1. If my UC symptoms are under control, there is not active disease or inflammation
   a. The answer is FALSE. Even if UC symptoms are under control, there may still be active disease or inflammation.

2. It is important to keep my disease under control to reduce long-term complications
   a. The answer is TRUE. It is important to keep UC under control to reduce long-term complications.

3. Uncontrolled inflammation is a risk factor for colorectal cancer
   a. The answer is TRUE. Uncontrolled inflammation is a risk factor for colorectal cancer.

4. UC may be associated with other conditions outside of my colon
   a. The answer is TRUE. UC may be associated with other conditions outside of the colon

5. It is okay to stop taking UC medications once you feel better
   a. The answer is FALSE. Even if you feel better, you should always consult your physician or healthcare provider before you stop taking UC medications.

6. It is okay to use steroids as long-term maintenance medication
   a. The answer is FALSE. Steroids should not be used as long-term maintenance medication.

7. It is possible for your body to stop responding to biologics, causing the medication to no longer work
   a. The answer is TRUE. It is possible for your body to stop responding to biologics, causing the medication to no longer work.

SECTION: DEMOGRAPHICS

BASE: ALL RESPONDENTS

Q462 Which of the following income categories best describes your total [INSERT LAST YEAR] household income before taxes?

178. Less than €5.000

179. €5.000 - €9.999

180. €10.000 - €19.999

181. €20.000 - €29.999

182. €30.000 - €39.999

183. €40.000 - €49.999

184. €50.000 - €74.999

185. €75.000 - €99.999

186. €100.000 - €149.999

187. €150.000 - €199.000

188. €200.000 or more

9994. Decline to answer

[r99] Unknown

BASE: ALL RESPONDENTS (Q280/18+ AND Q640/NE2 AND Q639/NE2)

Q364 What is your marital status?

1. Never married

2. Married or civil union

3. Divorced

4. Separated

5. Widow/Widower

6. Living with partner

BASE: ALL QUALIFIED FINLAND RESPONDENTS AND (dmCntry/75) AND Q640/NE2 AND Q639/NE2)

QFIREG In which region do you currently reside?

Choice:

[ch1] Attica (Athens)

[ch2] Central Greece

[ch3] Central Macedonia

[ch4] Crete

[ch5] East Macedonia, Thrace

[ch6] Epirus

[ch7] Ionian Islands
[ch8] Southern Aegean Sea
[ch9] Peloponnese
[ch10] Northern Aegean Sea
[ch11] Thessaly
[ch12] Western Greece
[ch13] Western Macedonia

SURVEY CLOSE - DISCLAIMER

[DISPLAY Q1230 BEFORE END SCREEN BUT AFTER ALL DEMOS]

BASE: **ALL QUALIFIED RESPONDENTS EX US (dmCntry/NE244)**

Q1230 Thank you for your participation in this survey! Throughout the survey there were many topics addressed that may or may not have applied to you. If you have any questions or concerns, please talk to your doctor or healthcare professional.

Supplementary material 2

UC Narrative Physicians Survey
GREECE

SECTION 600: SCREENER

BASE: **ALL RESPONDENTS**

Q8625 Thank you for agreeing to take this survey. Our first few questions are for classification purposes, and they enable us to select the questions to ask you later in the survey. They will also help us properly analyze responses to this survey. As you may already know, we never disclose the identity of any individual. Your answers will always be kept strictly confidential. We report results only for groups of people, not for individuals.

What is your primary medical specialty?

[RANDOMIZE]
18. Cardiovascular Diseases [TERMINATE]
32. Colon & Rectal Surgery [TERMINATE]
39. Dermatology [TERMINATE]
51. Gastroenterology
153. Rheumatology [TERMINATE]
173. Family Practice/General Practice [IF US:/Internal Medicine] [TERMINATE]
96. Other specialty ANCHOR [TERMINATE]
97. Unspecified specialty ANCHOR [TERMINATE]

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q8732 In what country is your practice located? If you practice in more than one country, please select the primary country in which you practice.
Choice:
[ch14] Australia
[ch33] Brazil

[ch42] Canada
[ch48] China
[ch75] Finland
[ch76] France
[ch85] Germany
[ch89] Greece
[ch116] India
[ch120] Ireland
[ch123] Italy
[ch126] Japan
[ch157] Mexico
[ch196] Russian Federation
[ch214] South Korea
[ch215] Spain
[ch223] Sweden
[ch224] Switzerland
[ch243] United Kingdom
[ch244] United States of America
[ch996] Other country

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q628 How many years have you been in your specialty practice?
[RANGE 0-100]
|_|_|_| years

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q8716 Which of the following best describes your medical practice?
1. Mostly office- or clinic-based
2. Mostly hospital- or lab-based
3. Exclusively hospital- or lab-based
4. Mostly long-term care facility-based [TERMINATE]
5. Mostly hospice-based [TERMINATE]
6. Equally hospital-based and office/clinic-based
96. Other [TERMINATE]

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q655 Do you currently practice in an IBD center/clinic?
Yes
No

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q657 Does your practice offer patients multidisciplinary care at one location?
1. Yes
2. No

BASE: **GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES**

Q656 Does your primary medical practice have IBD specialized nurse(s)?
Yes
No

BASE: GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES

Q630 Approximately how many unique adult patients (ages 18 and older) do you see in your practice each month who have the following conditions? For each condition, please think about all of the patients you see or treat per month. If you are not sure, please provide your best estimate.

Q631

[RANDOMIZE]   [RANGE: 0-1000]
1. Ulcerative colitis |_|_|_|_| patients [**TERMINATE IF LESS THAN 10**]
2. Irritable bowel syndrome |_|_|_|_| patients
3. Crohn's disease |_|_|_|_| patients
4. Celiac disease |_|_|_|_| patients

BASE: GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES WHO SEE UC PATIENTS

Q645 Approximately what proportion of your ulcerative colitis (UC) patients are currently being treated by the following types of prescription medications? Your best estimate is fine.

As patients may be on multiple therapies for their UC, the sum of these proportions may exceed 100%.

[RANGE 0-100]

Immunosuppressant (e.g., 6-Mercatopurine, Azathioprine, Methotrexate) |_|_|_|%

Anti-TNF biologic (e.g., Adalimumab (Humira), Golimumab (Simponi), Infliximab (Remicade, Inflectra)) |_|_|_|% [**TERMINATE IF 2 +3 LESS THAN 10%**]

Other biologic (e.g., Vedolizumab (Entyvio)) |_|_|_|% [**TERMINATE IF 2+3 LESS THAN 10%**]

5-ASA (e.g.,   (e.g., Salofalk, Pentasa, Asacol, Mezavant, Asalazine, Cronezil, Mesalazine)) |_|_|_|%

Corticosteroid (e.g., Prezolon, Medrol, Budecol, Budenofalk) |_|_|_|%

Other |_|_|_|%

Not currently taking prescription medication |_|_|_|%

[**MUST SUM TO AT LEAST 100%**]

BASE: GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES WHO SEE UC PATIENTS

Q646 Do you **personally** initiate biologic treatment in your ulcerative colitis patients?

1. Yes
2. No

BASE: GASTROENTEROLOGISTS AND OTHER QUALIFYING SPECIALTIES

Q650 This research is conducted on behalf of a pharmaceutical company. The pharmaceutical company is not a recipient of your personal data and, thus, did not have and shall have no access to your personal data. The pharmaceutical company shall only receive anonymized results which shall not be used to support measures or decisions

regarding you. This online questionnaire will be conducted in accordance with the Data Protection Act, Market Research Society, Association of the British Pharmaceutical Industry, and British Healthcare Business Intelligence Association guidelines.

Although this is an on-line market research survey and what you say will, of course, be treated in confidence, should you raise an adverse event in a specific patient or group of patients, we will need to report this even if it has already been reported by you directly to the company or the regulatory authorities [IF UK (Q8732/243) INSERT: using the MHRA's 'Yellow Card' system]. In such a situation, you will be asked whether or not you are willing to waive the confidentiality given to you under the Market Research Codes of Conduct specifically in relation to that adverse event.

Everything else you say during the course of the survey will continue to remain confidential, and you will still have the option to remain anonymous if you so wish.

Are you willing to proceed with the survey on this basis?
1. Yes
2. No [TERMINATE]

Qualified respondents will be:
- Resident of country of focus
- Specialize in Gastroenterology [varies by country as needed- outlined above]
- Not practicing in a long-term care facility or hospice (Q8716/4 or 5)
- See at least 10 UC patients in the past month
- At least 10% of patients are taking a biologic
- Agree to AE statement (Q650/1)

SECTION 700: Communication with Patients

BASE: ALL QUALIFIED RESPONDENTS (Q99/1)

Q700 You indicated that you have seen [INSERT RESPONSE FROM Q630/1] UC patients in the past month.

When answering the remaining questions in the survey, please think about your experiences treating patients in your practice whose UC is moderate to severe. By this, we mean patients who have ever taken more prescription medications than just 5-ASA to control their UC.

Please think of the patients you treat in the country where you consider your primary practice to be located.

BASE: ALL QUALIFIED RESPONDENTS

Q701 Approximately what proportion of your patients with moderate to severe UC are in the following age groups? Your best estimate is fine.

[RANGE: 0-100, SUM MUST EQUAL 100]

Under age 18 |_|_|_|%
Age 18-24 |_|_|_|%
Age 25-34 |_|_|_|%
Age 35-44 |_|_|_|%
Age 45-64 |_|_|_|%
Age 65+ |_|_|_|%

Q705   Based on what your patients tell you, what is important in managing their moderate to severe UC? Please select all that apply. [**Q715 in UC Patient Survey**]

[MULTIPLE RESPONSE; RANDOMIZE]

Be able to conduct daily activities

Be able to exercise

Have their disease controlled with alternative medicine

Prevent the need for injections or infusions

Reduce their risk of cancer

Reduce their fatigue

Attend school or work more often/consistently

Avoid colectomy or ostomy

Have less impact on familial or social relationships

Be able to eat whatever they would like without symptoms

Reduce the need for prescription medications

Avoid hospitalization

Be able to manage the psychological impacts of the disease (e.g., anxiety, depression, etc.)

Have less impact on sex life and personal relationships

Avoid toileting accidents, or the need to prepare for toileting accidents

Heal their mucosa

Be able to control their pain (e.g., abdominal, joint, etc.)

Be able to travel (for work or pleasure)

Minimizing or avoiding side effects from medication

Other [ANCHOR]

None [ANCHOR; EXCLUSIVE]

BASE: ALL QUALIFIED RESPONDENTS

Q710   Which of the following aspects, if any, do you discuss with your patients with moderate to severe UC? Please select all that apply.

[MULTIPLE RESPONSE; RANDOMIZE]

The impact of UC on patients' job/career/education or ability to attend work/school

The impact of UC on patients' mental/emotional health

The impact of UC on patients' ability to conceive (i.e., get pregnant)/father a child

Whether or not patients seek treatment from other healthcare professionals (e.g., primary care physician, physician assistant, internist, psychologist, [IF JAPAN (Q8732/126), INSERT: nurse; ALL OTHERS INSERT: nurse/nurse practitioner], pharmacist, dietitian etc.)

Patients' ability to afford their medication(s) [SUPPRESS IN FRANCE]

Patients' ability to adhere to their prescribed medication regimen

Patients' preference on medication type

The impact of UC on patients' sex life and personal relationships

Patients' ability to manage flares

Whether or not the patient has adequate support from family and friends

Patients' lifestyle goals for managing their UC (e.g., participate in a hobby, be able to travel)

Whether or not patients are interested in or should seek out complementary alternative treatments (e.g., XXX)

The difficulties my patients have in communicating aspects of their disease to those around them

The benefits and risks of treatment options

Patients' concerns about medication side effects

The information and support patient associations or organizations can provide

96.   Other   ANCHOR

97.   None   ANCHOR; E

BASE: ALL QUALIFIED RESPONDENTS

Q715   When do you typically discuss each of the following with your patients with moderate to severe UC?

Q716   [DISPLAY HORIZONTALLY]

Only at diagnosis/initial consultation

Only when making a change in medication

When the patient asks/initiates the discussion

On a regular basis as part of managing UC

At every visit

7.   Not sure

BASE: ALL QUALIFIED RESPONDENTS

Q720   Based on your conversations with your patients with moderate to severe UC, which of the following, if any, are your patients' top 3 worries because of their UC? [**Q720 in UC Patient Survey**]

[ALLOW UP TO THREE; RANDOMIZE]

That their UC might get worse

That their UC might cause other long-term health problems

The side effects they may experience from their prescription UC medication(s)

That they will not be able to get access to all available medications

How UC impacts their personal relationships

How UC impacts their career/education

The potential of needing a colectomy or ostomy in the future

The potential of passing UC on to their future children

The potential risk for developing cancer

That they may not be able to travel (for work or pleasure)

Other [ANCHOR]

None – my patients do not worry about anything because of their UC. [ANCHOR]

Not sure [ANCHOR]

That they will not be able to afford their medications

BASE: ALL QUALIFIED RESPONDENTS

Q725   With respect to your communication with your patients with moderate to severe UC, how much do you agree or disagree with each of the following statements?

Q726   [DISPLAY HORIZONTALLY]

Strongly disagree

Somewhat disagree

Somewhat agree

Strongly agree

[RANDOMIZE]

I wish my UC patients and I talked more about their UC treatment goals. [**Q1035 in UC Patient Survey**]

My patients understand their disease and the treatment options available.

I wish my patients understood the damage that long-term inflammation can have.

My patients are honest with me when discussing their experiences with UC. **[Q1035 in UC Patient Survey]**

I have taken steps to improve my communication skills with my patients (e.g., attended seminars, taken training courses, etc.). [SUPPRESS IN FRANCE]

I wish there was a way my patients could communicate with me more frequently while experiencing symptoms in between visits.

I wish my patients and I talked more about their fears of medical treatments. **[Q1035 in UC Patient Survey]**

I wish I had more time at appointments with my UC patients **[Q1035 in UC Patient Survey]**

I wish I had access to an IBD nurse to help me manage UC patients at my practice

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SECTION 800: Resources and Support

BASE: ALL QUALIFIED RESPONDENTS (Q99/1)
Q800 What proportion of your patients with moderate to severe UC do you recommend patient associations or organizations to as a source for information and support?
[RANGE 0-100]
|_|_|_|

BASE: ALL QUALIFIED RESPONDENTS
Q805 How well do you think your patients with moderate to severe UC understand each of the following aspects of UC? **[Q1130 in UC Patient Survey]**
Q806
Not at all
Not very well
Somewhat well
Very well

[RANDOMIZE]
1. Even if their UC symptoms are under control, they can still have active disease or inflammation.
2. It is important to keep their disease under control to reduce long-term complications.
3. Uncontrolled inflammation is a risk factor for colorectal cancer.
4. UC may be associated with other conditions outside their colon.
5. It is important to continue taking UC medications, even if they are feeling better.
6. Steroids should not be used as a long-term maintenance medication.
7. It is possible for their body to stop responding to biologics, causing the medication to no longer work.

SECTION 1000: General Treatment Perspective

BASE: ALL QUALIFIED RESPONDENTS
Q1000 How much do you agree or disagree with each of the following statements? Please continue to think about your experiences treating patients in your practice who have moderate to severe UC.
Q1001 [DISPLAY HORIZONTALLY]

Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

[RANDOMIZE]
UC patients who are involved in making treatment decisions tend to be more satisfied with their treatment experience than those who are not as involved.

UC patients often settle for a treatment that makes them feel "good enough" even though their disease is active or not well-controlled.

I wish my patients would talk to me before they stopped their medications.

I wish I had more time to discuss all available treatments earlier, so my patients had a better idea of their choices. **Q1035 in UC Patient Survey]**

I wish I moved more than half of my patients who are currently taking biologics to biologic therapy earlier than I did. (Prescribe biologics [all US respondents]).

More than half of my current biologic patients wish they had moved to biologic therapy sooner than they did. (Prescribe biologics [all US respondents]).

My patients are comfortable being on steroids as long as they feel better.

More than half of my patients take their prescriptions exactly as prescribed.

Q1002 How much do you agree or disagree with each of the following statements? Please continue to think about your experiences treating patients in your practice who have moderate to severe UC.
Q1002 [DISPLAY HORIZONTALLY]
1. Strongly disagree
2. Somewhat disagree
3. Somewhat agree
4. Strongly agree

[RANDOMIZE]
1. I rarely have time to address all of my UC patients' questions and concerns.
2. My patients feel comfortable raising concerns and fears with me.
3. I spend time discussing my patients' diet with them.
4. My patients feel comfortable talking to me about their emotional concerns.
5. My patients don't feel comfortable talking to me about their sex lives and personal relationship concerns.
6. Patient associations or organizations are important to the management of UC.
7. I wish there were resources I could refer my patients to for information and support.
8. More than half of my patients have requested cheaper medication alternatives.
9. My patients would prefer an effective oral medication over an injectable one if given the choice.

ALL QUALIFIED RESPONDENTS

Q1005 How much do you agree or disagree with each of the following statements? Please continue to think about your experiences treating patients with moderate to severe UC in your practice.

Q1006 [DISPLAY HORIZONTALLY]
Strongly disagree
Somewhat disagree
Somewhat agree
Strongly agree

[RANDOMIZE]
More than half of UC patients believe that pain and cramping are just part of living with UC
More than half of UC patients believe that spending significant time in the bathroom is just part of living with UC.
More than half of my UC patients have accepted that having UC means that they have to settle for a reduced quality of life.
My patients would approach their career or education differently if they did not have UC.
My patients would approach their personal relationships differently if they did not have UC.
More than half of UC patients believe that urgency in going to the bathroom is just part of living with UC.

BASE: **ALL QUALIFIED RESPONDENTS**

Q1010 What proportion of your patients with moderate to severe UC do you feel are satisfied with the communication they have with you regarding their UC? Your best estimate is fine. [**Q1015 in UC Patient Survey**]

[RANGE 0-100]   [SUM MUST =100]
Very dissatisfied|_|_|_| %
Somewhat dissatisfied |_|_|_| %
Somewhat satisfied |_|_|_| %
Very satisfied |_|_|_| %

BASE: **ALL QUALIFIED RESPONDENTS**

Q1015 Which of the following topics, if any, do you feel are the most important to prioritize during a routine appointment with your patients with moderate to severe UC? Please select up to three. [**Q1030 in UC Patient Survey**]

[SELECT UP TO THREE; RANDOMIZE]
The emotional impacts of UC [HOLD WITH CODE 3]
The physical impacts of UC [HOLD WITH CODE 2]
The impacts of UC on sex life and personal relationships
How to control inflammation
What to expect next from their UC treatment, including possible changes in treatment
New medications that are available for UC
Side effects of current treatment
Symptoms experienced since their last visit
What to expect from their UC long-term
If they could get cancer

Their ability to afford their medications
Their ability to manage fatigue
Their ability to manage symptoms
Where to go for information and support
Other [ANCHOR]
None [ANCHOR; EXCLUSIVE

BASE: **ALL QUALIFIED RESPONDENTS**

Q1020 In thinking about your patients with moderate to severe UC, which of the following, if any, would help to improve your patient relationships? Please select all that apply. [**Q1050 in the patient study**]

[MULTIPLE RESPONSE; RANDOMIZE BUT KEEP 1 & 2, 3& 4 TOGETHER]
More frequent visits
Longer visits
More information about UC in general to give to my patients
More information about the UC treatment options that are available to give to my patients
More tools to help my patients prepare for their visits with me (e.g., list of questions to ask, informative brochures)
Clarity on their personal treatment goals and whether or not they are meeting them
Discussion of whether or not they take their medication(s) exactly as prescribed
An online tool or smartphone application to better monitor and track their activities and symptoms
Advice on where to get reliable information to help them manage their disease
A list of other health care professionals in my area (e.g., psychologists, nutritionists, IBD nurse, rheumatologist, dermatologist) to which I could refer my patients to aid in UC treatment
The ability to refer my patients to chronic disease management classes
A tool explaining the mechanics of how UC actually works
Other methods of communication (e.g., telephone, video conversations, email, etc.)
Better access to colonoscopies
Having informed resources to provide to my patients
Having an IBD nurse to help with management
96.   Other   ANCHOR
97.   Nothing would help improve my patient relationships   ANCHOR, E

SECTION 1100: General Medication

BASE: **ALL QUALIFIED RESPONDENTS**

Q1100 What proportion of your patients with moderate to severe UC do you feel are satisfied with their current medications? Your best estimate is fine. [**Q1105 in UC Patient Survey**]

[RANGE 0-100]   [SUM MUST =100]
Very dissatisfied|_|_|_| %
Somewhat dissatisfied |_|_|_| %
Somewhat satisfied |_|_|_| %
Very satisfied |_|_|_| %

BASE: ALL QUALIFIED RESPONDENTS

Q1105 Turning your attention to medication specifically, which of the following do you typically do to determine if your patients are satisfied with their medication regimen? Please continue to think about your experiences treating patients with moderate to severe UC in your practice. Please select all that apply.

[MULTIPLE RESPONSE; RANDOMIZE]

I wait for the patient to tell me if they are satisfied or not.

I ask the patient directly if they are satisfied or not.

I ask the patient if they are experiencing any side effects.

I ask the patient how their medication regimen impacts various aspects of their personal life.

I ask the patient if they are satisfied with the mode of administration (i.e., orally vs. injection vs. infusion).

I ask the patient how they feel before and after initiating the medication.

Based on the symptoms patients describe

I ask them if they are taking their medications as prescribed

I ask the patient if they are satisfied with the frequency of administration.

96. Other   ANCHOR

97. Nothing   ANCHOR; E

BASE: ALL QUALIFIED RESPONDENTS

Q1110 Approximately what proportion of your patients with moderate to severe UC do you feel are well controlled with few to no symptoms by their current UC medication regimen? Please provide your best estimate.

[RANGE: 0 – 100]

|__|__|__|%

SECTION 1200: Changes in medication regimen

BASE: ALL QUALIFIED RESPONDENTS

Q1200 When thinking about the UC medications that are currently available, what are the **top three** things patients tell you that indicate that it is time to consider changing medications? Please select up to three. [**Q1205 in UC Patient Survey**]

[SELECT UP TO THREE; RANDOMIZE]

1. The patient is having continued symptoms
2. Having to adjust the dose multiple times
3. The patient is unable to do the things they want to do
4. The patient is having continued flares
5. The patient is needing to make additional visits to [Q149/1:myself] [Q149/2: you] or another health care professional
6. The patient is having to stop taking a medication because they cannot tolerate the side effects
7. The patient is unable to go to work or school consistently
8. The patient is needing to go to the hospital or emergency room unexpectedly
9. The patient frequently is calling the office to express concerns or ask questions
10. The patient's joints are starting to bother them
11. The cost of medications/changes in affordability
12. There are changes in availability of medications
13. The patient experiences increased urgency and frequency of stools
14. The patient is unable to tolerate the mode of administration (i.e., oral, injectable, infusion)
15. The patient is missing too much work or school to get their medicine
16. The current medicine is too inconvenient
17. The patient hears from someone else about a different medication option
18. The patient desires to have children
96. Other   [ANCHOR]
97. None   [ANCHOR, EXCLUSIVE]

BASE: HAVE EVER RECOMMENDED CHANGE

Q1210 For which of the following reasons, if any, have your patients with moderate to severe UC been reluctant when you recommend or make a change in their medication regimen? Please select all that apply. [**Q1220 in UC Patient Survey**]

[MULTIPLE RESPONSE; RANDOMIZE]

They were worried about the side effects from the new medication

They were afraid that the new medication would not be any better

The medications were expensive

They didn't like the way the new treatment would be administered (e.g., infusion vs. injection vs. oral medication, etc.)

They thought their current medication was treating their UC well enough

Their insurance makes it difficult to change medications [SUPPRESS IN CANADA, FINLAND]

They were afraid of the long-term risks

They were afraid of the possibility of experiencing fertility issues in the future

They did not understand why I recommended the change

The change was mandated by the health care system

They were worried about getting pregnant and managing pregnancy

96. Some other reason   [ANCHOR]

97. My patients never feel reluctant when I recommend a change in medication [ANCHOR; EXCLUSIVE]

BASE: BIO-PRESCRIBING HCPS

Q1215 To what extent, if any, would each of the following make you hesitate to prescribe patients with moderate to severe UC an **anti-TNF biologic therapy**?

Examples of anti-TNF biologics include: Adalimumab (Humira), Golimumab (Simponi), Infliximab (Remicade, Inflectra).

Q1216 Would hesitate, but would <u>not prevent</u> me from initiating new treatment

Would hesitate and would prevent me from initiating new treatment

Would not hesitate because of this

[MULTIPLE RESPONSE; RANDOMIZE]
Concerns about the side effects of these medications
Fear of the potential long-term risks
Feeling the patient is doing well enough on their current medication [HOLD WITH CODE 4]
Feeling the patient is controlled on their current medication [HOLD WITH CODE 3]
Patients may decline to move to anti-TNF biologic therapy
I would want more information about the medication before initiating new treatment
The possible financial burden on the patient
Not covered by their health care plan/insurance
The impact of UC on patients' ability to conceive (i.e., get pregnant)/father a child

BASE: **BIO-PRESCRIBING HCPS**

Q1220 To what extent, if any, would each of the following make you hesitate to prescribe patients with moderate to severe UC an **anti-integrin biologic therapy**?

Examples of an anti-integrin biologic include vedolizumab (Entyvio).

Q1221 Would hesitate, but would not prevent me from initiating new treatment
Would hesitate and would prevent me from initiating new treatment
Would not hesitate because of this
[MULTIPLE RESPONSE; RANDOMIZE]
Concerns about the side effects of these medications
Afraid of the potential long-term risks
Feeling the patient is doing well enough on their current medication [HOLD WITH CODE 4]
Feeling the patient is controlled on their current medication [HOLD WITH CODE 3]
Patients may decline to move to anti-integrin biologic therapy
I would want more information about the medication before initiating new treatment
The possible financial burden on the patient
Not covered by their health care plan/insurance
The impact of UC on patients' ability to conceive (i.e., get pregnant)/father a child

BASE: **DO NOT PERSONALLY PRESCRIBE BIOLOGICS**
Q1222 Earlier you mentioned that you do not personally initiate biologic treatment for your UC patients. Do you ever discuss biologic treatment with your UC patients?
Yes
No

Q1300. Have you completed a fellowship in IBD?
1. Yes
2. No

Q8702. Are you..?
1. Male
2. Female

Q8705. Age
Q8710. In what year did you graduate from medical school?
Q8712. In what year did you complete your residency?
Q8719. How would you describe your office or clinic?
1. Private office
2. Private clinic or medical team of the same specialty (2 or more doctors)
3. Private clinic or medical team of different specialties (2 or more doctors)

Q8722. On average, how many patients do you see in a typical week? If you are not sure, your best estimate will do.
Q8725. Which of the following best describes the ages of your patient population?
1. Age ≤ 18 (pediatrics)
2. Age 19 - 64 (adults)
3. Age ≥ 19 (adults and elderly)
4. Age ≥ 65 (elderly)
5. All ages

Q8728. On average, about how many prescriptions do you write (or medications do you dispense) in a week? If you are not sure, your best estimate will do.