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# Gaps Between European Crohn's Colitis Organisation Quality Standards of Care and the Real World in Special Situations in Inflammatory Bowel Disease Across Europe: Results From E-QUALITY Survey

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## ABSTRACT

**Background:** Managing special situations in Inflammatory Bowel Disease (IBD)—such as surgery, nutrition, acute severe ulcerative colitis (ASUC) and paediatric-to-adult transition—is critical for patient outcomes. The European Crohn's and Colitis

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Organisation's (ECCO) E-QUALITY initiative aimed to identify gaps between its evidence-based care standards and real-world clinical practice in these key areas.

**Methods:** The E-QUALITY Taskforce conducted a web-based survey across ECCO members. Data on institutional protocols and processes for surgery, nutrition, ASUC, paediatric-to-adult transition management were collected from 245 institutions across 35 European countries.

**Results:** The survey revealed significant heterogeneity in practice. Laparoscopic surgery for major IBD-related bowel surgery was the preferred approach in 72% of institutions. Post-operative recurrence prevention was reported in 57% of institutions. Pre-operative nutritional screening for all surgical patients was standard in only 40% of institutions. For ASUC, a time-bound, multidisciplinary management algorithm was in place in 30% of institutions. Only 35% of centres had a formal pathway for paediatric-to-adult transition. Guideline adherence was generally higher in larger, academic hospitals.

**Conclusion:** Substantial gaps exist between ECCO recommendations and real-world clinical practice for managing these special IBD situations. These findings highlight an urgent need for targeted advocacy and educational initiatives for healthcare professionals, providers and patients to standardise care and improve outcomes in IBD management across Europe.

### Plain Language Summary

The E-QUALITY survey conducted by the European Crohn's and Colitis Organisation (ECCO) across 245 European hospitals showed significant variations in how doctors manage key situations in inflammatory bowel disease (IBD), both among institutions and among European geographical regions.

The results showed that although most hospitals (72%) use less invasive laparoscopic surgery, important steps are often missed. For example, only 40% of institutions regularly check a patient's nutrition before surgery and less than half (43%) consistently work to prevent the disease from coming back after an operation. The survey also revealed that a formal plan for managing severe flare-ups is followed in just 30% of hospitals and only 35% have a structured program to help young patients transition from children to adult care.

These findings highlight a substantial gap between what is recommended and what happens in real life, suggesting an urgent need to standardise care across Europe.

## 1 | Introduction

Inflammatory bowel diseases (IBD), such as Crohn's disease (CD) and ulcerative colitis (UC), are chronic diseases [1–3], with complications including strictures, fistulas, abscesses and acute severe disease, which often require surgery [2]. Outcomes of surgery in terms of hospitalisation length, prevention of post-operative complications and rate of readmission after surgery depend on several factors, including the use of concomitant systemic corticosteroids [2–4] and pre-operative nutritional status [5]. Evidence on the importance of achieving good nutritional status in IBD patients is increasing, especially in terms of prevention of side effects and loss of effectiveness of therapies [6]. Acute severe ulcerative colitis (ASUC) is a life-threatening situation where appropriate timing of therapies and a well-structured multidisciplinary approach impact outcome [2–4]. Finally, IBD patients with early onset disease require appropriate transition to adult care, as patient needs and management strategies often change [7, 8].

The European Crohn's and Colitis Organisation (ECCO) has developed several evidence-based guidelines on the above mentioned special situations [1–12] and there is also a position paper on quality-of-care standards [13]. However, gaps exist in healthcare when clinicians are unaware of, unable to apply or unwilling to use the most current evidence in their decision making.

To identify these gaps, ECCO launched the E-QUALITY initiative to improve the quality of care for patients living with

IBD [14]. ECCO members who served in ECCO committees or are committed as national experts in the field of IBD were selected to be part of the E-QUALITY task force to identify the gaps between the desired quality of care standards and real-world practice.

Due to the large amount of data coming from the two phases of this survey, data on the structure of IBD units and data on diagnosing and monitoring IBD have been reported in separate manuscripts [15, 16]. This report will focus on special situations, such as the management of surgery, nutrition, acute severe ulcerative colitis and paediatric-to-adult transition.

## 2 | Materials and Methods

The E-QUALITY Taskforce developed a web survey accessible to all ECCO members which answered on behalf of their institutions across Europe only. To avoid duplicates from the same institutions, only one person from each institution could answer the survey on behalf of their team. Not only physicians, but also nurses, trainees, surgeons or any member of the team were allowed to answer the questions. Answers were based on that person's opinion alone and no evidence was required to substantiate their answers. Recruitment was open from September 2022 to October 2024. There was a central double-check mechanism to ensure only one survey per institution was completed and that the person replying was a legitimate representative of the institution.

The web survey was split into two phases: the first investigated the structure of IBD units [15] and the second investigated processes in the participating institutions [16], mainly based on a previous systematic review [17], the ECCO position paper on quality-of-care standards [13] and the current ECCO recommendations [1–12, 18, 19]. The survey also included questions on the existing barriers to providing adequate quality of care standards. Most questions consisted of multiple-choice options, trying to capture whether a specific standard was adopted by internal protocol, followed or not in the majority of cases or even if compliance was guaranteed through internal/external audit mechanisms. When responders answered that they have a standard internal protocol followed in the majority of cases and guaranteed by an internal/external audit mechanism, this answer was considered a sign of adherence to the QoC standards. A descriptive analysis of the survey using frequencies and percentages was performed. Secondary analyses highlighted differences between institutions based on the number of IBD patients under active follow-up, the type of institutions (academic, non-academic, public or private hospitals/clinics) and geographical location (Northern, Western, Southern and Eastern Europe) [15, 16]. Since geographical characterisation may be challenging to define, this was based on international organisation lists (such as the United Nations [20] or the World Health Organisation [21]) and the previous ECCO pan-European epidemiological studies [15, 16, 22, 23]. The chi-square test was used to compare data between the categories as mentioned above. Statistically significant differences were considered as per the  $p$ -value < 0.05. Statistical analyses were performed using Jamovi, version 2.5.6 (<https://www.jamovi.org>).

## 2.1 | Ethic Statement

Since this was a survey from institutions with no individual patients' data, approval from ethical committees was not required.

## 3 | Results

Two hundred and forty-five institutions from 35 European countries responded to the survey [15, 16]. The numbers by country and their geographical distribution and details about the characteristics of the participating institutions have been previously listed [15]. Relevant characteristics of institutions are reported in Table 1 and in our previous publications from the same project [15, 16].

### 3.1 | Surgical Management of IBD Patients

Laparoscopic approach was the preferred approach for scheduled IBD surgery in 174 (72%) institutions. For patients with perianal fistulising disease, a combined medical/surgical approach was taken in 162 (66%) institutions. Strictureplasty was routinely performed to treat short small bowel strictures in 131 (54%) institutions. Temporary ostomy was the preferred approach, when corticosteroids could not be withdrawn or tapered under 20 mg/day of prednisone or equivalent, in 61 (25%) institutions.

The rate of temporary ileostomy after elective ileo-caecal resection was higher than 20% in 11 institutions (5%). Pre-operative reduction of corticosteroid below prednisolone 20 mg daily is routinely attempted for semi-elective or elective surgery in 137 (51%) institutions.

Preventive therapies for post-operative recurrence based on individual risk assessment were offered in 175 (63%) institutions. Endoscopic assessment of post-operative recurrence 6–12 months after an ileocolic resection was considered standard of care and was guaranteed by established procedures in 136 (57%) institutions. Endoscopy with biopsies was routinely performed in patients with pouch-related symptoms in 184 (77%) institutions.

**TABLE 1** | Relevant characteristics of institutions participating in the E-QUALITY survey ( $n = 245$ ).

| Characteristic  | N (%)    |
|---|----------|
| At least one surgeon with a subspecialist interest in IBD                     | 194 (80) |
| Clear referral pathway for complex IBD surgery                                | 195 (80) |
| Surgical procedures for IBD per year  |          |
| < 10  | 45 (19)  |
| 10–50   | 118 (48) |
| 50–100  | 47 (19)  |
| > 100   | 35 (14)  |
| Number of restorative proctectomies (including ileo-anal pouch—IPAA) per year |          |
| 1–2   | 37 (16)  |
| 3–5   | 50 (21)  |
| 6–9   | 20 (8)   |
| ≥ 10  | 53 (22)  |
| Not offered—Patients referred to another institution                          | 77 (33)  |
| At least one dietician/nutritionist with a subspecialist interest in IBD      | 144 (59) |
| Clear pathway for referral if a dietician/nutritionist is not present         | 85 (64)  |

In those institutions where prevention of post-operative recurrence was not the standard approach, 22 of them responded about the main reasons why this is not offered. These reasons were: clinicians not prescribing therapies for prevention (32%); patients prefer not to take any medication after surgery (55%); patients cannot afford it because of insurance/reimbursement issues (14%).

### 3.2 | Management of Nutritional Aspects

In patients with an indication for IBD-related surgery, screening for pre-operative nutritional status was performed in all patients in 97 (40%) of the institutions. The main reasons for not screening all patients were: some clinicians/surgeons do not request nutritional screening (59%), the institution cannot provide all tests in a timely fashion (17%) or lack of adequate staff in the institution (24%).

This pre-operative screening was however routinely done in patients with malnutrition in 201 (83%) institutions. Pre-operative optimisation of nutritional status in patients with CD was performed by enteral or parenteral nutrition in 123 (51%) institutions, whereas pre-operative optimisation of nutritional status in patients with UC was performed in 188 (78%) institutions. The main reasons why pre-operative optimisation was not done were: some clinicians/surgeons do not request nutritional optimisation (54%), nutritional optimisation cannot be done in a timely fashion (25%) or patients do not adhere to the nutritional optimisation (21%). Except for preoperative optimisation of nutritional status in CD patients (OR 2.05,  $p = 0.009$ ), there was no association between these approaches and the presence of a dietician/nutritionist in the unit. In regard to the overall IBD population, nutritional status, such as iron, B12, folate, albumin and vitamin D serum levels and anaemia, were assessed routinely at least once a year or during a flare in 167 (69%) institutions, independently from the presence/absence of a dietician/nutritionist. Assessment for bone loss in patients at increased risk of metabolic bone disease (i.e., prolonged use of systemic corticosteroids) was routinely done in 71 (29%) institutions. The main reasons why this was not the standard approach were: some clinicians do not prescribe the tests (60%), institutions cannot provide the tests in a timely fashion (26%), patients do not adhere to the prescriptions (7%) or cannot afford them because these are too expensive or not reimbursed (7%).

### 3.3 | Acute Severe Ulcerative Colitis

In patients hospitalised for ASUC, a time-bound algorithm was followed in 72 (30%) institutions. Combined multidisciplinary management by gastroenterologists and surgeons since day 1 was the standard approach in 72 (30%) institutions. In 12 institutions (5%), patients with ASUC are managed by the gastroenterologist and the surgeon is contacted only if the patient presents with toxic megacolon, bowel perforation or massive bleeding. In 80 institutions (33%), patients are managed by the gastroenterologist and the surgeon is contacted when the patient fails steroids and/or rescue therapy. In the remaining 81

institutions (32%), the surgeon is contacted at day 1, but this does not happen every time or there are no mechanisms to guarantee this. Systematic thromboprophylaxis for hospitalised patients was the standard procedure in 150 (62%) institutions. A rescue medical therapy (infliximab or cyclosporin) was considered at day 3 in steroid-refractory patients in 156 (65%) institutions.

### 3.4 | Paediatric-to-Adult Transition

As previously reported [22], a transition clinic was present in 56% of institutions; however, in only 85 (35%) institutions is this a formally organised clinic or a clearly established pathway. In all responding institutions where transition was reported ( $n = 135$ ), transition was organised by: a face-to-face discussion with the adult, the paediatric team and the patient in 98 (72%) institutions; a face-to-face discussion with the adult, the paediatric team, but without the patient in 14 (10%) institutions; email or phone discussion between the teams, but without the patient, in 119 (88%) institutions; multidisciplinary team (MDT) meeting, without the patient in 7 (5%) institutions. Paediatric IBD clinicians usually join the MDT discussion in 62 (26%) institutions.

Transition occurs at the legal age without no exception in 35 (15%) institutions, at the legal age, but with some exceptions and joint management overlap between the adult and the paediatric team for a while in 137 (57%) institutions, whereas in 15 institutions (6%) there is no mandatory age and transition depends on patient's preference and in 54 (22%) it depends on the clinician's decision.

### 3.5 | Subgroup Analyses

Significant differences in surgical procedures across European regions are reported in Tables 2–4. In particular, units located in Northern and Western Europe were more likely to report adherence to the standards of surgical management than those in Southern and Eastern Europe. Units in Southern and Western Europe were more likely to claim checking for nutritional status at least once a year or during a flare, compared to those in Northern Europe. Management of ASUC was more adherent to the standards in Northern Europe than in the rest of the European centres.

Institutions with > 500 patients in active follow up were more likely to: perform a temporary ostomy for patients unable to withdraw or taper corticosteroids < 20 mg/day of prednisolone or equivalent (0.002); screen for nutritional status those patients with malnutrition undergoing surgery ( $p = 0.027$ ), use rescue medical therapies at day 3 in steroid-refractory patients with ASUC ( $p = 0.035$ ), manage patients with ASUC jointly by the gastroenterologist and the surgeon from day 1 of hospitalisation ( $p = 0.007$ ) and to have a formally organised transition clinic or a clear pathway for transition ( $p = 0.003$ ). University hospitals were more likely to: use rescue medical therapies at day 3 in steroid-refractory patients with ASUC ( $p = 0.005$ ), follow a time bound algorithm for ASUC (0.023), screen all patients for

**TABLE 2** | Statistically significant differences in the surgical management of IBD patients among European regions.

|   | % institutions | Z    | p value |
|---|----------------|------|---------|
| Laparoscopic approach for scheduled IBD surgery                                 |                |      |         |
| Northern Europe-Southern Europe   | 81 versus 62   | 2.38 | 0.017   |
| Northern Europe-Eastern Europe  | 81 versus 44   | 3.21 | 0.001   |
| Western Europe-Southern Europe  | 91 versus 62   | 3.89 | < 0.001 |
| Western Europe-Eastern Europe   | 91 versus 44   | 4.44 | < 0.001 |
| Stricturoplasty routinely used to treat short small bowel strictures            |                |      |         |
| Northern Europe-Eastern Europe  | 63 versus 37   | 2.16 | 0.031   |
| Western Europe-Eastern Europe   | 62 versus 37   | 2.22 | 0.026   |
| Temporary ostomy in patients who cannot withdraw/taper steroids below 20 mg/day |                |      |         |
| Northern Europe-Southern Europe   | 39 versus 19   | 2.45 | 0.014   |
| Endoscopy is performed within 6–12 months after surgery                         |                |      |         |
| Southern Europe-Northern Europe   | 62 versus 41   | 2.44 | 0.015   |

**TABLE 3** | Statistically significant differences in the nutritional management of IBD patients among European regions.

|  | % institutions | Z    | p value |
|--|----------------|------|---------|
| Nutritional status assessed at least once a year or during a flare |                |      |         |
| Southern Europe-Northern Europe                                    | 79 versus 49   | 3.55 | < 0.001 |
| Southern Europe-Eastern Europe                                     | 79 versus 51   | 2.68 | 0.007   |
| Western Europe-Northern Europe                                     | 76 versus 49   | 3.01 | 0.003   |
| Western Europe-Eastern Europe                                      | 76 versus 51   | 2.30 | 0.021   |

**TABLE 4** | Statistically significant differences in the management of acute severe ulcerative colitis (ASUC) in IBD patients among European regions.

|   | % institutions | Z    | p value |
|---|----------------|------|---------|
| Time bound algorithm used in ASUC   |                |      |         |
| Northern Europe-Western Europe  | 43 versus 21   | 2.46 | 0.014   |
| Rescue therapy considered at day 3 in steroid-refractory patients with ASUC |                |      |         |
| Northern Europe-Eastern Europe  | 76 versus 44   | 2.64 | 0.008   |
| Southern Europe-Eastern Europe  | 70 versus 44   | 2.40 | 0.016   |
| Venous thromboprophylaxis for patients hospitalised for ASUC                |                |      |         |
| Northern Europe-Southern Europe   | 80 versus 63   | 1.99 | 0.047   |
| Northern Europe-Eastern Europe  | 80 versus 48   | 2.74 | 0.006   |
| Northern Europe-Western Europe  | 80 versus 53   | 2.81 | 0.005   |

nutritional status before surgery ( $p < 0.001$ ), use enteral or parenteral nutrition to optimise the nutritional status prior to surgery ( $p = 0.025$ ) and to have a formally organised clinic or a clear pathway for referral for transition ( $p < 0.001$ ).

#### 4 | Discussion

As highlighted in the previous reports from the E-QUALITY survey [22, 23], important gaps between ECCO recommendations and real-world practice were also found in special situations. Our survey reported that there are wide heterogeneity and

deficiencies in the approach to surgery, nutrition, ASUC and paediatric-to-adult transition.

With respect to surgery, the roles of optimisation of nutrition, preferably driven by a dietician/nutritionist included in the MDT [5, 6] and the importance to withdraw systemic corticosteroids are well established in order to avoid post-surgical complications, such as anastomotic leak or infections [2, 4]. However, our survey reveals that this approach is not the standard in about half of the institutions, although about 80% of institutions do screen their patients when they have malnutrition and prescribe nutritional optimisation, especially in patients with UC. As previously reported [15, 16], lack of a

uniform approach between physicians in the same institutions, challenges in getting optimisation in a timely fashion and lack of adherence from patients are the main reasons why this is not done. These limitations may be taken into account by guidelines, especially when recommendations are not supported by high quality evidence.

Laparoscopic approach, combined medical/surgery approach to perianal fistulising disease and strictureplasties for short small bowel strictures are considered the standard in < 75% of institutions. We did not investigate why these approaches are not adopted, but we can speculate that not all institutions have dedicated surgeons or pathways for referral [15] and that probably more efforts are needed to disseminate guidelines and to standardise surgical approaches. For this reason, exchange programs among surgeons may also be helpful.

Prevention and early detection of post-operative recurrence is not routinely performed in about 50% of institutions. Advanced therapies may be expensive and not reimbursed in patients with no current active disease, but we also demonstrated that in more than 50% of cases, patients prefer not to take medications with preventative purpose alone. In this case, collaboration between scientific societies and patients' associations is important to increase awareness and knowledge in the patient community. In a smaller but still important percentage of cases, the role of patients is crucial in adhering to optimisation of nutritional status and protection of bone health, especially when increased risk factors are present (i.e., prolonged use of corticosteroids). Therefore, education improvement and support for both healthcare professionals and patients in order to increase adherence to international standards is pivotal to raise quality of care.

The management of ASUC by a well-defined algorithm has been standardised for decades [24]. Despite this, we found that this standard approach is routinely followed in no more than two-thirds of institutions. ASUC is a special situation where UC can progress to severe complications (including death) in a short time frame. Therefore, following standard procedures in all patients is crucial. Efforts in education and standardisation are clearly still needed, especially in non-academic institutions and in those who follow < 500 patients, as there is probably a lack of sufficient practical expertise in this challenging setting.

Finally, efforts are needed in paediatric-to-adult transition, as we found that this particular situation is managed in a very heterogeneous way with only a third of institutions having a defined pathway for transition. A focus on improving or facilitating transition pathways appears to be an area of need.

Our previous reports from the same project [15, 16] show that lack of time, lack of money, lack of people and difficulties in requesting tests for diagnosis and monitoring in a timely fashion were the main barriers to achieve the desired quality of care standards. These barriers are also true for the special situations discussed in this paper. We could not investigate in detail whether differences between ECCO and national guidelines or healthcare systems may impact on these gaps, however this is going to be investigated further in next projects in collaboration with ECCO National Representatives.

Our survey has some limitations. All answers were self-reported and there was no possibility to verify whether auditing mechanisms were present to confirm the given responses. This will be discussed as a basis for future projects by ECCO. Secondly, we did not investigate several challenges arising from this survey in a more detailed way. This will probably be investigated in the near future. The risk of confirmation bias cannot be excluded. However, the large number of participating institutions, the adopted strategies to reduce duplicates or contradictory responses and the support of the E-QUALITY taskforce members at the local level to help respondents to correctly understand the aims and the structure of this survey may be considered some strengths of this project. ECCO will increase its efforts focusing on the gaps revealed by this survey with the ultimate goal to improve quality of care in IBD. Some actions, such as dedicated educational programs on gaps in quality of care, collaboration with national representatives to adapt this project to country-specific needs, collaboration with patients' association in joint projects [15, 16], may be helpful to reduce the gaps. Advocacy aimed at healthcare providers, payers and decision and policy makers is also worthwhile as some barriers to quality improvement are rooted in lack of funding/reimbursement.

## 5 | Conclusion

The E-QUALITY survey identified important gaps between the desired quality-of-care standards and real-world practice in surgery, nutrition, acute severe ulcerative colitis (ASUC) and paediatric-to-adult transition. More efforts are needed to improve education and support for both healthcare professionals and patients in order to improve adherence to standard and the quality of care in IBD.

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### Author Contributions

Gionata Fiorino led the project, performed the statistical analyses and drafted the manuscript. Alissa Walsh and Catarina Fidalgo coordinated the project and drafted the web surveys. All Authors revised the surveys, enrolled the participating institutions, planned the statistical analysis and critically revised the data and the manuscript. All Authors approved the final version of the manuscript.

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### Conflicts of Interest

Gionata Fiorino served as a consultant and Advisory Board member for Takeda, Abbvie, Janssen, Pfizer, Celltrion, Sandoz, Ferring, Galapagos, Alfasigma, STADA, Eli Lilly; Alissa Walsh received grants from AbbVie, BMS, Buhmann, Helmsley Trust, Janssen, Lilly, Pfizer, Takeda and Norman Collisson Foundation, consultancy fees from AbbVie, Buhmann, Falk, Ferring, Janssen, Lilly, Pfizer, Takeda and speaker fee from

AbbVie, Falk, Ferring, Janssen, Lilly; Pfizer, Shire, Takeda; Manuel Barreiro-de Acosta received fees as a speaker, consultant and advisory member or has received research funding from MSD, AbbVie, Janssen, Kern Pharma, Celltrion, Takeda, GALAPAGOS, Pfizer, Sandoz, Biogen, Fresenius, Lilly, Ferring, Faes Farma, Dr. Falk Pharma, Chiesi, Gebro Pharma, Adaclyte and Vifor Pharma; Johan Burisch received grants from Janssen, MSD, Takeda, Tillots Pharma, BMS, Novo Nordisk and consultancy fees from Celgene, MSD, Pfizer, AbbVie, Takeda, Tillots Pharma, Samsung Bioepis, BMS, Pharmacosmos, Galapagos; Axel Dignass reports fees for participation in clinical trials, review activities such as data monitoring boards, statistical analysis and end point committees from Abivax, AbbVie, Bristol Myers Squibb, Dr Falk Foundation, Galapagos, Gilead, Janssen and Pfizer; consultancy fees from AbbVie, Alfasigma, Amgen, Biogen, Boehringer Ingelheim, Bristol Myers Squibb, Celltrion, Dr Falk Foundation, Ferring Pharmaceuticals, Fresenius Kabi, Galapagos, J&J, Lilly, MSD, Pfizer, Pharmacosmos, Sandoz, Stada, Takeda, Tillots and Vifor Pharma; payment from lectures including service on speakers bureaus from AbbVie, Alfasigma, Biogen, CED Service GmbH, Celltrion, Falk Foundation, Ferring, Galapagos, Gilead, High5MD, Janssen, Materia Prima, MedToday, MSD, Pfizer, Streamed-Up, Takeda, Tillots and Vifor Pharma; payment for manuscript preparation from Abbvie, Falk Foundation, J&J, Takeda, Thieme and UniMed Verlag. David Drobne received grants from MSD and consultancy fees from Abbvie, Amgen, Biogen, Janssen, Krka, MSD, Pfizer, Takeda; Marc Ferrante received grants from AbbVie, Biogen, EG, Janssen, Pfizer, Takeda and Viatrix, consultancy fees from AbbVie, AgomAb Therapeutics, Boehringer Ingelheim, Celgene, Celltrion, Eli Lilly, Janssen-Cilag, MRM Health, MSD, Pfizer, Takeda and ThermoFisher; Lihi Godny received grants from Helmsley Charitable Trust and consultancy fees from Abbvie, Takeda, Pfizer, Janssen, Galapagos, Altman; Marietta Iacucci received grants from Pentax, Olympus, Ely Lilly and consultancy fees from Pentax, Pfizer, Galapagos; Konstantinos Karmiris has served as speaker, consultant and/or advisory board member for Abbvie, Amgen, Bristol Myers Squibb, Ferring, Galenica, Genesis, Janssen, MSD, Pfizer, Roche, Takeda and Vianex; Julien Kirchgerner received lecture fees from Pfizer, Janssen and Lilly and consulting fees from Roche, Pfizer, Gilead, Takeda, Abbvie, Celltrion, Galapagos, Janssen, Pfizer, Tillots and Lilly; Sophie Restellini received speaker and/or advisory board member fees from AbbVie, Janssen, Takeda, Bristol Myers Squibb, Sandoz, Vifor, Dr Falk, iQone, Lilly and UCB; Dror Shouval received grants and lecture fees from Takeda; Henit Yanai received grants from Pfizer, ISF and consultancy fees from AbbVie, Janssen, Pfizer, Takeda and Bristol Myers Squibb and Eli Lilly; Edyta Zagórowicz received speaker fees from Abbvie, Eli Lilly, Bristol Myers Squibb, Takeda and Janssen and consultancy or advisory board member fees from Janssen, Eli Lilly; Susanna Jäghult received speaker fees from Orion Pharma, Takeda Pharmaceuticals, Eli Lilly; the other Authors declare no conflict of interests.

#### Data Availability Statement

The authors have nothing to report.

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## Appendix 1

**TABLE A1** | List of participating institutions.

| Hospital   | Country |
|--|---------|
| Mother Teresa Hospital Center                          | Albania |
| Mikaelyan University Hospital                          | Armenia |
| Klinik Landstrasse                                     | Austria |
| Medical University Graz                                | Austria |
| Medical University Vienna                              | Austria |
| ASZ Aalst  | Belgium |
| AZ Damiaan   | Belgium |
| AZ Delta   | Belgium |
| AZ Groeninge   | Belgium |
| AZ Herentals   | Belgium |
| AZ Maria Middelaes                                     | Belgium |
| AZ Rivierenland  | Belgium |
| AZ Sint Jan  | Belgium |
| AZ Sint-Lucas  | Belgium |
| AZ Sint-Lucas Gent                                     | Belgium |
| AZ Sint-Maarten  | Belgium |
| AZ Turnhout vzw  | Belgium |
| AZ Vesalius  | Belgium |
| AZ Voorkempen  | Belgium |
| CHU Charleroi  | Belgium |
| CHU Liège  | Belgium |
| CSL-Arlon  | Belgium |
| Grand Hôpital de Charleroi                             | Belgium |
| Heilighartziekenhuis Lier                              | Belgium |
| Hopital Erasme   | Belgium |
| Imelda Hospital  | Belgium |
| Mariaziekenhuis  | Belgium |
| OLV Ziekenhuis Aalst                                   | Belgium |
| Pediatric Gastroenterology Antwerp University Hospital | Belgium |
| Sint-Andriesziekenhuis                                 | Belgium |
| Sint-Franciscus Ziekenhuis Heusden                     | Belgium |
| Sint-Jozefskliniek Izegem                              | Belgium |
| Sint-Trudo Ziekenhuis                                  | Belgium |
| University Hospital Antwerp                            | Belgium |
| UZ Brussel   | Belgium |

(Continues)

**TABLE A1** | (Continued)

| <b>Hospital</b>                                    | <b>Country</b> |
|--|----------------|
| UZ Gent  | Belgium        |
| UZ Leuven  | Belgium        |
| Vitaz  | Belgium        |
| ZOL Maas en Kempen                                 | Belgium        |
| Military Medical Academy                           | Bulgaria       |
| UMHAT Tsaritsa Yoanna-ISUL                         | Bulgaria       |
| General Zadar Hospital                             | Croatia        |
| UCH SESTRE Milosrdnice                             | Croatia        |
| University Hospital Zagreb                         | Croatia        |
| American Gastroenterology Center Cyprus            | Cyprus         |
| Ceske Budejovice                                   | Czech Republic |
| IBD Clinical and Research Centre ISCARE a.s.       | Czech Republic |
| Aalborg University Hospital                        | Denmark        |
| Aarhus University Hospital                         | Denmark        |
| Bispebjerg Hospital                                | Denmark        |
| Copenhagen University Hospital Rigshospitalet      | Denmark        |
| Gødstrup Hospital                                  | Denmark        |
| Herlev and Gentofte Hospital                       | Denmark        |
| Hospital of South West Denmark Esbjerg             | Denmark        |
| Amager and Hvidovre Hospital                       | Denmark        |
| Lillebaelt Hospital                                | Denmark        |
| Regional Hospital Silkeborg                        | Denmark        |
| Regionshospitalet Viborg                           | Denmark        |
| Slagelse Regional Hospital                         | Denmark        |
| Zealand University Hospital                        | Denmark        |
| East-Tallin Central Hospital                       | Estonia        |
| Tartu Ülikooli Kliinikum                           | Estonia        |
| West Tallinn Central Hospital                      | Estonia        |
| Children's Hospital Helsinki                       | Finland        |
| Helsinki University Hospital                       | Finland        |
| Bordeaux University Hospital                       | France         |
| CHU Dijon  | France         |
| CHU Toulouse Rangueil                              | France         |
| Gastroenterology Unit—Poitiers University Hospital | France         |
| Grenoble Alpes                                     | France         |
| Henri Mondor                                       | France         |
| Hopital Saint-Louis Paris                          | France         |
| Hospital Louis-Mourier                             | France         |
| Hospital Saint Antoine                             | France         |
| Toulouse University Hospital                       | France         |
| Charité Campus Benjamin Franklin                   | Germany        |
| German Red Cross Hospital Berlin Westend           | Germany        |
| Isarklinikum and VIVAQ-MVZ                         | Germany        |
| MVZ for Immunology                                 | Germany        |
| MVZ Gastroenterologie                              | Germany        |
| Universitätsklinikum Augsburg                      | Germany        |
| University Hospital Dresden                        | Germany        |

(Continues)

**TABLE A1** | (Continued)

| Hospital  | Country |
|---|---------|
| University Hospital Erlangen  | Germany |
| University Hospital Frankfurt   | Germany |
| University Medical Center Freiburg  | Germany |
| Zentrum für Gastroenterologie Saar MVZ GmbH   | Germany |
| 401 General Military Hospital of Athens   | Greece  |
| Agia Sophia Children's Hospital   | Greece  |
| Agios Nikolaos General Hospital   | Greece  |
| AHEPA General University Hospital of Thessaloniki   | Greece  |
| Athens Medical Center   | Greece  |
| Athens Medical Paleo Faliron Hospital   | Greece  |
| Attikon University Hospital   | Greece  |
| Gastroenterology Department Alexandra General Hospital  | Greece  |
| General Hospital Nikaia Piraeus Agios Panteleimon—General Hospital Dytikis Attikis Agia Varvara | Greece  |
| General Hospital of Athens G. Gennimatas  | Greece  |
| General Hospital of Kavala  | Greece  |
| GHA 'Evangelismos-Ophthalmiatreion Athinon, Polykliniki'  | Greece  |
| Hippokration General Hospital   | Greece  |
| Hippokration Hospital   | Greece  |
| Interbalkan Medical Center of Thessaloniki Greece   | Greece  |
| Metaxa Memorial Hospital  | Greece  |
| Metropolitan General Hospital—Department of Advanced Therapeutic                                | Greece  |
| Saint George—General Hospital of Chania   | Greece  |
| Theagenio Anticancer Hospital of Thessaloniki   | Greece  |
| Tzaneio General Hospital  | Greece  |
| University Hospital of Alexandroupolis  | Greece  |
| University Hospital of Heraklion  | Greece  |
| University Hospital of Larisa   | Greece  |
| Venizeleio General Hospital   | Greece  |
| Cork University Hospital  | Ireland |
| Mater University Hospital   | Ireland |
| St Vincent's University Hospital  | Ireland |
| Hadassah Medical Center   | Israel  |
| Kaplan Medical Center   | Israel  |
| Rabin Medical Center  | Israel  |
| Sheba Medical Center Ramat Gan Israel   | Israel  |
| Soroka University Medical Center  | Israel  |
| Tel Aviv Sourasky Medical Center  | Israel  |
| A.O.U. Policlinico San Marco—Catania  | Italy   |
| Arnas G.Brotzu  | Italy   |
| ASST Lariana—Ospedale Sant'Anna   | Italy   |
| Azienda Ospedale Università di Padova   | Italy   |
| Ca' Foncello  | Italy   |
| Careggi University Hospital   | Italy   |
| Casa Sollievo della Sofferenza  | Italy   |
| Cattinara Hospital  | Italy   |
| Fondazione Policlinico Agostino Gemelli IRCCS   | Italy   |

(Continues)

**TABLE A1** | (Continued)

| Hospital  | Country     |
|---|-------------|
| IBD-Unit Ospedali Riuniti Rivoli  | Italy       |
| IRCCS Azienda Ospedaliero-Universitaria di Bologna—Policlinico di S. Orsola | Italy       |
| IRCCS Fondazione San Gerardo dei Tintori                                    | Italy       |
| IRCCS Sacro Cuore Don Calabria Negrar                                       | Italy       |
| IRCCS San Donato IBD Unit   | Italy       |
| IRCCS San Raffaele Hospital   | Italy       |
| Istituto Clinico Humanitas  | Italy       |
| Maggiore Hospital   | Italy       |
| Manzoni Hospital  | Italy       |
| Mauriziano Hospital   | Italy       |
| Ospedale Bernardo Ramazzini di Carpi—AUSL Modena                            | Italy       |
| Ospedale Luigi Sacco  | Italy       |
| Ospedale Maurizio Bufalini Cesena   | Italy       |
| Ospedale San Filippo Neri   | Italy       |
| Pediatric Gastroenterology Unit—Umberto I Hospital                          | Italy       |
| Policlinico Messina   | Italy       |
| Policlinico Palermo   | Italy       |
| Policlinico Universitario di Monserrato (CA)                                | Italy       |
| Rho Hospital—ASST Rhodense  | Italy       |
| San Bortolo Hospital  | Italy       |
| San Camillo-Forlanini   | Italy       |
| San Gerardo Hospital University of Milan Bicocca                            | Italy       |
| Santa Maria della Misericordia di Perugia                                   | Italy       |
| University General Hospital—Renato Dulbecco                                 | Italy       |
| University ‘Tor Vergata’ of Rome  | Italy       |
| University Federico II of Naples  | Italy       |
| University Hospital L. Vanvitelli   | Italy       |
| UOSD Endoscopia—PO Alto Vicentino   | Italy       |
| Valduce Hospital  | Italy       |
| Pauls Stradins Clinical University Hospital                                 | Latvia      |
| Lithuanian university of health sciences                                    | Lithuania   |
| Mater Dei Hospital  | Malta       |
| Timofei Moşneaga Republican Clinical Hospital                               | Moldova     |
| Erasmus MC  | Netherlands |
| Franciscus Gasthuis & Vlietland   | Netherlands |
| Radboudumc  | Netherlands |
| Reinier de Graaf Gasthuis   | Netherlands |
| Oslo University Hospital  | Norway      |
| Copernicus Hospital   | Poland      |
| Heliodor Święcicki Univeristy Hospital in Poznań                            | Poland      |
| Kliniczny Szpital Wojewódzki Nr 2   | Poland      |
| Maria Skłodowska-Curie National Research Institute of Oncology              | Poland      |
| Oddział Gastroenterologii i Chorób Wewnętrznych                             | Poland      |
| Silesian Medical University   | Poland      |
| Centro Hospitalar do Oeste  | Portugal    |
| Centro Hospitalar Lisboa Ocidental  | Portugal    |
| Centro Hospitalar Vila Nova de Gaia Espinho                                 | Portugal    |

(Continues)

**TABLE A1** | (Continued)

| Hospital  | Country            |
|---|--------------------|
| Hospital Beatriz Ângelo   | Portugal           |
| Hospital do Divino Espírito Santo de Ponta Delgada                | Portugal           |
| Hospital Dr Nélio de Mendonça                                     | Portugal           |
| Hospital Espírito Santo Évora                                     | Portugal           |
| Hospital Garcia de Orta   | Portugal           |
| Hospital Santa Maria—Centro Hospitalar Universitário Lisboa Norte | Portugal           |
| Hospital Santo António Capuchos—CHULC                             | Portugal           |
| Instituto Portugues de Oncologia de Lisboa Francisco Gentil       | Portugal           |
| University Hospital Center of São João                            | Portugal           |
| Fundeni Clinical Institute  | Romania            |
| A. S. Loginov Moscow Clinical Scientific Center                   | Russian Federation |
| Scandinavia Clinic  | Russian Federation |
| CHC Dragisa Misovic   | Serbia             |
| University Hospital Medical Center ‘Zvezdara’                     | Serbia             |
| Bezrucova Medical Center  | Slovakia           |
| Celje General Hospital  | Slovenia           |
| General Hospital Jesenice   | Slovenia           |
| University Medical Center Maribor                                 | Slovenia           |
| University Medical Centre of Ljubljana                            | Slovenia           |
| Corporació Sanitària Universitària Parc Taulí                     | Spain              |
| Hospital Clínico Universitario de Santiago                        | Spain              |
| Hospital Clínico Universitario San Carlos                         | Spain              |
| Hospital Universitari Mútua Terrassa                              | Spain              |
| Hospital Universitario de Galdakao                                | Spain              |
| Hospital Universitario de La Princesa                             | Spain              |
| Hospital Universitario de Valencia                                | Spain              |
| Capio Gastro Center Stockholm                                     | Sweden             |
| County Hospital Ryhov   | Sweden             |
| Ersta sjukhus   | Sweden             |
| Karolinska University Hospital                                    | Sweden             |
| Linköping University Hospital                                     | Sweden             |
| Örebro University Hospital  | Sweden             |
| Sahlgrenska University Hospital                                   | Sweden             |
| Södersjukhuset  | Sweden             |
| Södersjukhuset—Sachsska Children and Youth Hospital               | Sweden             |
| Umeå University Hospital  | Sweden             |
| Center of Gastroenterology and Hepatology                         | Switzerland        |
| Clarunis and University Hospital Basel                            | Switzerland        |
| Groupe medical d'onex   | Switzerland        |
| Kantonsspital Winterthur  | Switzerland        |
| La Tour Hospital  | Switzerland        |
| Lausanne Digestive Disease Center-Hirslanden                      | Switzerland        |
| Ankara University Medical School                                  | Turkey             |
| Ankara University School of Medicine                              | Turkey             |
| Gazi University School of Medicine                                | Turkey             |
| Hacettepe University  | Turkey             |
| İstanbul Medeniyet University                                     | Turkey             |

(Continues)

**TABLE A1** | (Continued)

| <b>Hospital</b>  | <b>Country</b> |
|--|----------------|
| Liv Vadi Hospital                                      | Turkey         |
| Mersin University Faculty of Medicine Hospital         | Turkey         |
| Barnet Hospital Royal Free London NHS Foundation Trust | United Kingdom |
| Cambridge University Hospitals NHS Foundation Trust    | United Kingdom |
| Chelsea and Westminster Hospital                       | United Kingdom |
| Great Western Hospital NHS FT                          | United Kingdom |
| Guy's & St Thomas' NHS Foundation Trust                | United Kingdom |
| Hampshire Hospitals NHS Foundation Trust               | United Kingdom |
| Hillingdon Hospital NHS Foundation Trust               | United Kingdom |
| Hull University Teaching Hospital                      | United Kingdom |
| John Radcliffe Hospital                                | United Kingdom |
| Milton Keynes University Hospital NHS Trust            | United Kingdom |
| North Bristol Trust Southmead Hospital                 | United Kingdom |
| Queen Elizabeth University Hospital                    | United Kingdom |
| Royal Devon & Exeter                                   | United Kingdom |
| Sheffield Teaching Hospital NHS Foundation Trust       | United Kingdom |
| St Mark's Hospital                                     | United Kingdom |
| St Richard's Hospital, University Hospitals Sussex     | United Kingdom |
| Stoke Mandeville Hospital                              | United Kingdom |
| The Royal London, Barts Health NHS trust               | United Kingdom |
| Ulster Hospital Dundonald                              | United Kingdom |
| University Hospital Bristol and Weston NHS Trust       | United Kingdom |
| Worthing Hospital                                      | United Kingdom |