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Original Article

Gaps between European Crohn's Colitis Organisation quality standards of care and the real world on structure of IBD units across Europe: results from E-QUALITY survey

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Abstract

Background and aims: Inflammatory bowel diseases (IBD), including Crohn's disease and ulcerative colitis, require an interdisciplinary approach for diagnosis, monitoring, and management. The European Crohn's and Colitis Organisation (ECCO) has developed evidence-based recommendations and quality care standards for IBD management, but gaps between these standards and real-world practice persist. The E-QUALITY task force aimed to evaluate the structure, processes, and outcomes of IBD units across Europe and identify barriers to achieving ECCO quality standards.

Methods: A web-based survey was conducted from September 2022 to October 2024 among 245 institutions in 35 European countries. The survey assessed unit structure, interdisciplinary care, services, facilities, and barriers to achieving quality care standards. Subgroup analyses were performed based on institution type, patient volume, and geographical distribution.

Results: Formal IBD units were present in 68% of institutions, with interdisciplinary teams available in 94%. Institutions with >500 active patients were more likely to meet ECCO standards for interdisciplinary care, quality indicators, and patient support but faced challenges such as lack of time and referral pathways. Geographical disparities significantly influenced the availability of resources and services. Key barriers to quality care included lack of time (71%), personnel (69%), and funding (45%).

Conclusions: Significant gaps in quality care standards remain across European IBD units. Enhanced support from ECCO, by education and position papers/guidelines may help bridge these gaps.

Key words: quality of care; inflammatory bowel disease; Crohn's disease; ulcerative colitis

1. Introduction

Inflammatory bowel diseases (IBDs), such as Crohn's disease (CD) and ulcerative colitis, are complex chronic diseases, which require an interdisciplinary approach.[1,2] Diagnosis of IBD is based on clinical, laboratory, endoscopic, cross-sectional imaging-based, and histological findings,[3] which require the combination of expertise by different specialist physicians. Monitoring of IBD to assess response to therapies, disease progression, and development of complications is also based on different parameters, as it happens for diagnosis.[3] IBD also may progress to complications, such as strictures, fistulas, abscesses, perianal lesions, and malignancies which usually require surgery.[4] Nutrition, mental health related to these chronic conditions, and increased risk of infections or other complications related to impaired immune response, and transition from pediatric to adult care for youngest patients, are also key aspects of IBD management.[5–8]

In the last 2 decades, the European Crohn's and Colitis Organisation (ECCO) has developed and regularly updated evidence-based recommendations on the key topics related to IBD management.[1–14] Besides evidence-based publications, ECCO also published a position paper on quality-of-care (QoC) standards, which should be the minimum level of QoC to provide to patients with IBD.[1] Since ECCO is an international scientific organization, recommendations might be not completely consistent with national and local situations or regulations; therefore, important gaps may be present between these recommendations and real-world practice.

For these reasons, ECCO launched the E-QUALITY initiative to ultimately improve the QoC of patients living with IBD.[15] A dedicated task force of ECCO members, who served in ECCO committees, or are committed as national experts in the field of IBD, is in charge of developing projects with the purpose to reduce the gap between the desired QoC standards and the real-world practice.

2. Materials and methods

The E-QUALITY Taskforce developed a web survey accessible to all institutions affiliated with ECCO across Europe. Each institution was invited by email to participate. Only 1 delegate per institution was requested to respond to the questions listed in the web questionnaire. To improve the dissemination of the initiative and recruitment of institutions, each member of the Taskforce was responsible to reach out national IBD groups affiliated to ECCO in their own country or in neighbor countries, preferably speaking the same or similar languages to improve communication about the purposes and the conduct of this project. To avoid any duplication in data, and to avoid unallowed access from persons/entities outside the identified responder, every participant should apply by sending a response to the invitation to the ECCO Office. The ECCO Office, after verification of all requisites, sent back the link to the web platform with the instructions to access by a unique user ID and password. As the hosting platform was the same one used for the UR-CARE initiative, those responders affiliated to an institution which already joined the UR-CARE were allowed to use the same user ID and password they used to access that project. Participants were also directly recruited at the ECCO booth during the ECCO congresses or at the United European Gastroenterology Week congress, where they could apply to the project and could receive a direct link to the web survey, as all verifications were done on-site. Recruitment was open from September 2022 to October 2024.

The web survey was split into 2 phases: 1 investigating the structure of IBD units and 1 investigating processes and outcomes in the participating institutions, mainly based on the ECCO position paper on QoC standards,[1] and on the current ECCO recommendations.[2–4,6–14] Among the possible answers, one was consistent with ECCO-relevant recommendations and was used as a reference for the primary and secondary analysis to identify adherence to ECCO recommendations. The survey also included questions on the existing barriers to provide adequate QoC standards and questions on how ECCO could help in overcoming such obstacles. In this paper, we will present the data focused on structure. Another paper is dedicated to processes and outcomes.

A descriptive analysis was performed on the results of the web survey. Subanalyses on all items were conducted to highlight differences between institutions based on the number of IBD patients under active follow-up, the type of institutions (academic, nonacademic, public or private hospitals/clinic), and geographical location (Northern, Western, Southern, and Eastern Europe, Table S1). Since geographical characterization may be challenging, this was based on international organization lists (such as the United Nations[16] or the World Health Organisation[17]), and on the previous ECCO epidemiological studies.[18,19] Chi-square test was used to compare data between the above-mentioned categories. Differences were considered statistically significant for $P < .05$.

3. Results

Two-hundred forty-five institutions from 35 European countries responded to the survey. The numbers by country and their geographical distribution are detailed in Figures S1 and S2. Details about the characteristics of the participating institutions are shown in Table 1.

In 68% of cases, there was a formally identified IBD Unit, and 94% of them provided an interdisciplinary approach to patients. The interdisciplinary team (MDT) included at least 1 identified physician in 89% of cases, 1 nurse in 69% of cases, 1 surgeon in 80% of cases, 1 pathologist in 66% of cases, 1 radiologist in 71% of cases, 1 dietician/nutritionist in 59% of cases, 1 stoma specialist in 61% of cases, and 1 endoscopist in 95% of cases. In those units where one identified person was not present, in 80%, there was a clear pathway for complex IBD surgery in 80% of cases, a clear pathway for referring a patient to a dietician/nutritionist in 64% of cases, and a pathway for a stoma specialist in 61% of cases. In 31% of units, there was an identified psychologist, and in 47% of cases a clear pathway for referral. Access to a subspecialist (ie, rheumatologist, dermatologist) was present in 92% of institutions (Figure 1).

Table 1. Characteristics of the responder institutions.

Type of institution (n = 245)	Number (%)
Private clinic	7 (2.9)
Private hospital	15 (6.2)
Public clinic	3 (1.2)
Public hospital	88 (36.7)
University hospital	126 (52.5)
None of the above	1 (0.4)
Number of IBD patients regularly followed up	
<100	7 (2.9)
100–500	56 (23.0)
500–1000	64 (26.3)
1000–1500	33 (13.6)
>1500	83 (34.2)

In regards to service and facilities (Figure 2), 79% provide a sufficient number of appointments to meet demand, and 66% have administrative support for appointments. Infusion units are present in 91% of institutions, 67% of those who do not have in-house infusion clinics have a clear referral pathway externally, 86% are linked to emergency department in the same hospital, and 91% can provide admission to the hospital. Among responders, 98% usually make an individual treatment plan, 76% have a structured plan for early recognition of flares, 67% schedule regular MDT meetings, and 56% can provide transition clinics. Patient-reported outcome measures (PROMs) are regularly measured in 43% of institutions. Direct contact between patients and units is provided in 95% of institutions (89% by telephone, 82% by email, 19% by web portals, 12% by dedicated apps, 2% with none of these tools), remote follow-up is possible in 83% of them (83% by telephone, 62% by emails,12% by web portals, 10% by dedicated apps, 21% by video calls), virtual clinics are done in only 16% of institutions. Patient database is present in 77% of institutions, 54% of them use a specific institutional database, 39% use Excel, 22% national databases, 9% the UR-CARE platform, 7% other kinds of platform, and 4% Access.

In 73% of institutions, 1 MDT member is in charge for education, counseling, emotional support, liaison, and continuity, 68% have a named lead of the IBD unit, 62% develop in-house guidelines for the management of IBD patients, 42% have identified quality indicators to monitor QoC, 37%

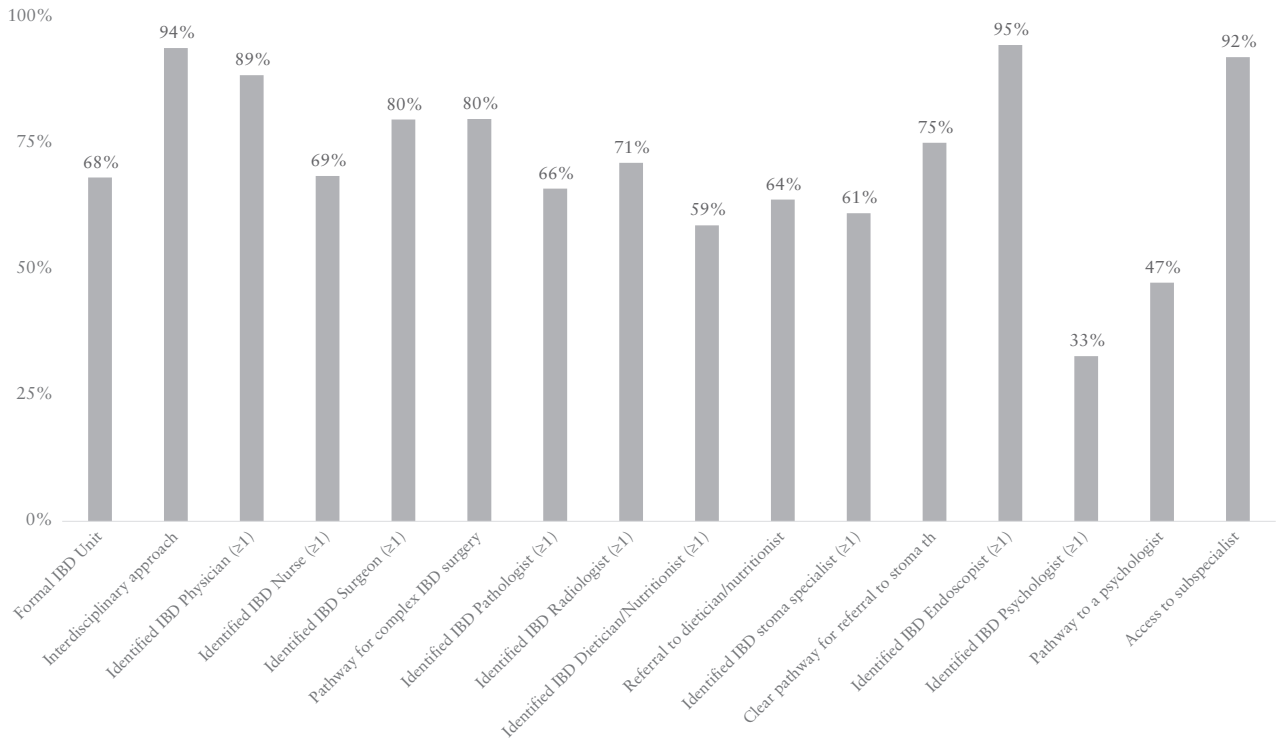

Figure 1. Structure of IBD units (n = 245).

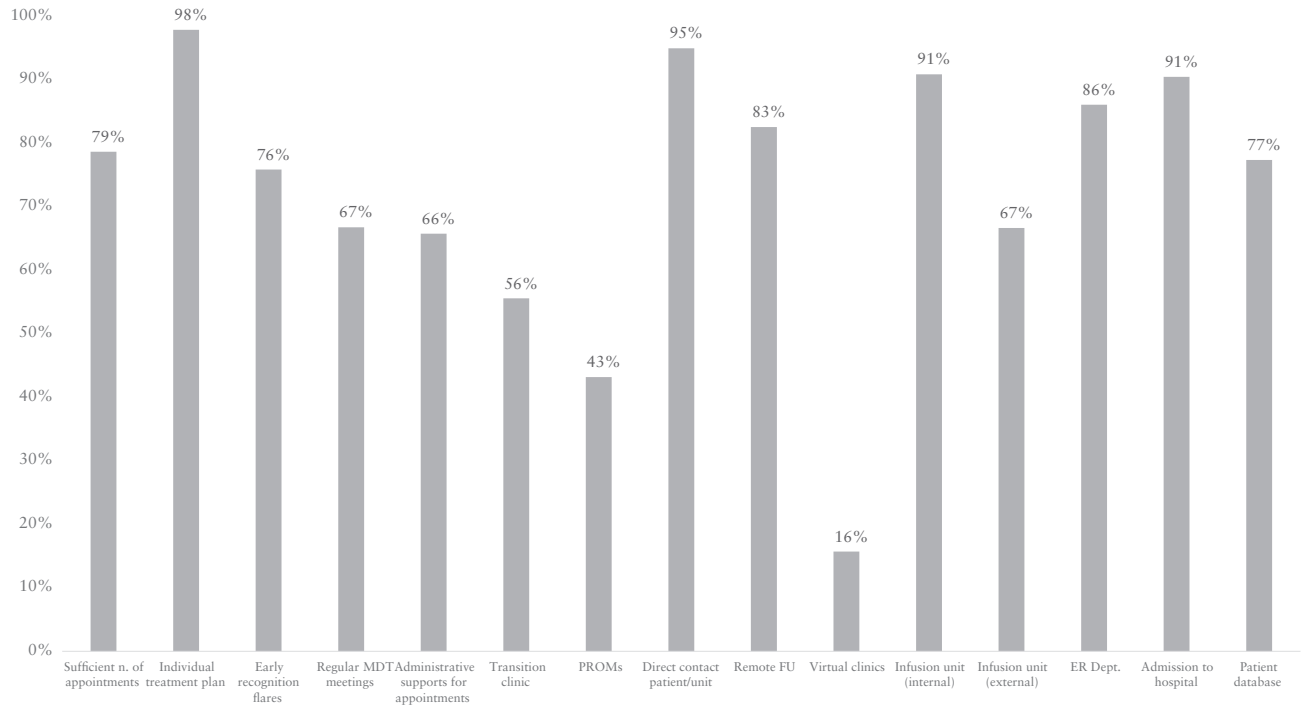

Figure 2. Service and facilities in IBD Units (n = 245).

generally register the defined minimum set of quality indicators and delivers data (anonymized) for benchmarking and practice variation assessment, whereas 41% do this specifically for surgical procedures; 42% do collect feedback about patient satisfaction (Figure 3).

Participants were asked which are the main challenges in achieving QoC standards in their own institutions: 71% responded lack of time, 69% lack of people, 45% lack of money, 22% lack of interest from their institution, 17% no interest from other specialists, 16% lack of identified referral pathways, 10% country-specific regulations, 8% lack of specific education, 5% other challenges (not specified). For the responders, ECCO can help in overcoming these barriers by supporting educational national programs (55%), position papers or guidelines (55%), promoting and supporting UR-CARE (42%), international educational programs (37%), data production (23%), other (nonspecified, 5%).

3. Subgroup analyses

There were no significant differences between university hospitals and other kinds of institutions, except for the presence of a specialist surgeon (P = .020). On the other hand, institutions with >500 patients in active follow-up were more likely to have a formally identified IBD unit (P < .001), to provide an interdisciplinary approach to the patient (P < .001), with an identified specialist physician (P = .02), a specialist IBD nurse (P < .001), a surgeon (0.001), a pathologist (P = .008), a radiologist (P < .001), a stoma management specialist (P < .001), an MDT member who provides patient education, counseling, emotional support, liaison, and continuity (P = .013), a named lead for the service (P = .007), in-house departmental guidelines (P = .003), quality indicators (P = .011), interdisciplinary case review (P = .007) and regular MDT meetings (P < .001), direct contact line (0.022), outpatient facilities to administer intravenous medical therapies (P = .001), hospital emergency department (P = .018), administrative support for active management of appointments (0.005), a transition clinic (P < .001), use of PROMs (P < .001), collaboration with patients' associations (P = .002), whereas these institutions were less likely to provide a sufficient number of outpatient appointments to meet demand (P = .023), and to register the defined minimum set of quality indicators and deliver data for benchmarking and practice variation assessments (P = .006). Institutions with >500 patients in active follow-up identified lack of time and lack of referral pathways as the main challenges to achieve QoC standards, significantly more frequently than other categories, and identified the launch and maintaining participation in the UR-CARE registry as the main support from ECCO to overcome these challenges (P < .001). We also found that the presence of at least 1 IBD nurse is associated with an increased probability to have a member of the MDT providing patient education, counseling, emotional support, liaison, and continuity in patient care (OR 4.98, 95% CI, 2.71–9.17, P < .001).

Statistically significant differences were found in structure, service, and facilities according to the geographical distribution of institutions. We present these differences in Tables S2–S6.

4. Discussion

This survey revealed a robust commitment among European institutions to interdisciplinary care, as we found that formally identified IBD units were present in 68% of institutions, and 94% of these provided an interdisciplinary approach. The vast majority of institutions have an identified specialist physician (89%), endoscopists (95%), and surgeons (80%), and provide access to subspecialists (ie, rheumatologists, dermatologists) for complex cases. However, despite all efforts by

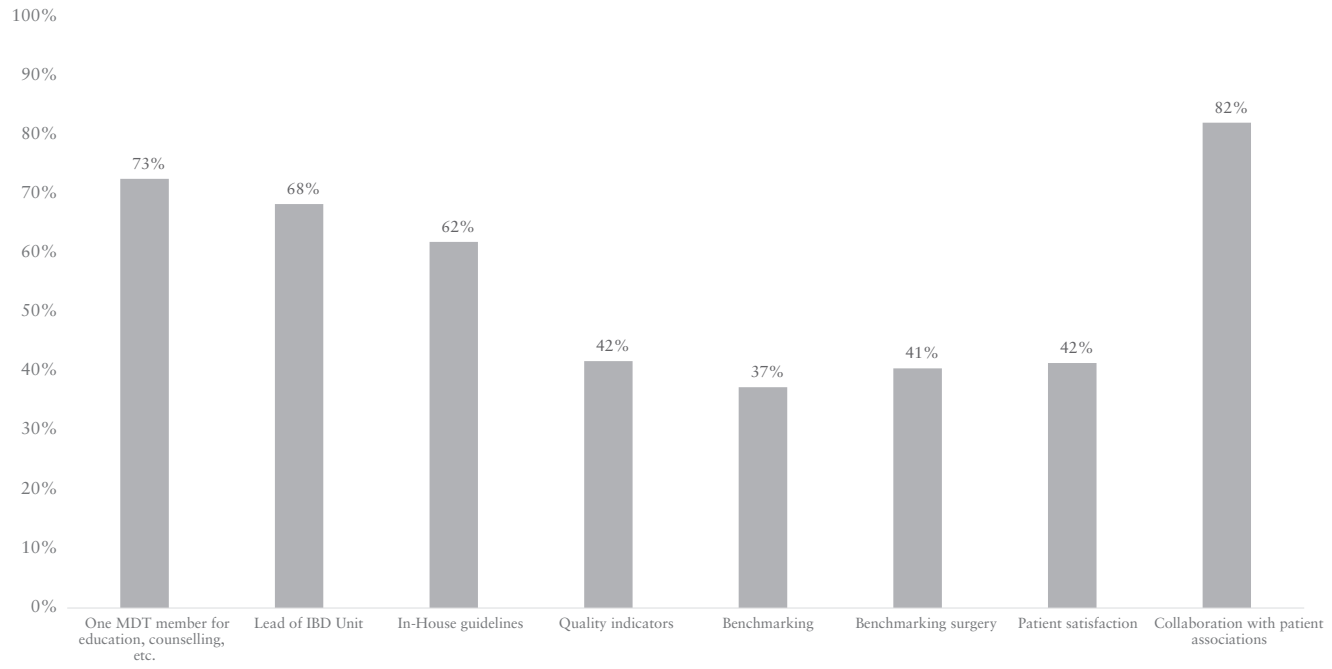

Figure 3. Quality assessment (n = 245).

ECCO in supporting key nonmedical MDT members even with dedicated initiatives by specific committees, the number of specialized nurses (69%), stoma specialists (61%), pathologists (60%), and dieticians/nutritionists (59%) still needs improvement, especially in Southern and Eastern Europe. Infusion units and hospital admission facilities were available in over 90% of institutions, and most centers (98%) reported the creation of individual treatment plans, a critical factor in personalized medicine. Direct patient communication was prioritized, with 95% of institutions offering contact through phone or email. Remote follow-up, an increasingly vital service in modern healthcare, was feasible in 83% of institutions. Moreover, where an identified specialist is not present in the unit or in the same institution, clear pathways for referral are present in most cases (from 64% for dieticians to 80% for complex surgery). This means that the vast majority of patients can receive adequate QoC across Europe. Despite these encouraging results, still only 31% of institutions employed a psychologist, with another 47% providing a referral pathway, suggesting insufficient integration of mental health care, which is considered important for IBD patients, and, more generally, for any chronic condition. Similarly, the use of PROMs, a tool for capturing patient perspectives, was reported in only 43% of institutions, reflecting missed opportunities for patient-centered care. Institutions from Southern, Eastern, and Western Europe are more likely to have a psychologist or a referral pathway than Northern Europe; however, on the other hand, institutions from Northern Europe are more likely to have one MDT member who provides patient education, counseling, emotional support, liaison needs to be easily understandable for providers and patients, changeable by behavior, achievable, and measurable with high validity and continuity. This is probably indirect evidence that 2 models of managing mental well-being for IBD patients are followed in Europe. The statistically significant association between having at least 1 IBD nurse and providing patient education, counseling, emotional support, liaison, and continuity supports and confirms the essential role of the IBD nurse, and the need to fund education, and recruitment of nurses in every unit which aims to provide good QoC to patients with IBD. Geographical disparities were generally found in IBD management, as institutions in Northern and Western Europe were more likely to report higher QoC standards overall compared to Southern and Eastern ones. These differences should be taken into consideration when international initiatives should be planned in order to approach different situations in a more tailored way.

The main challenges to achieve and maintain recommended QoC standards included lack of time (71%), lack of people (69%), and lack of financial resources (45%). Institutions following up larger patient cohorts (>500) were more likely to face challenges in terms of time to provide all quality standards. Although these larger centers did provide interdisciplinary approaches and adequate infrastructure, they reported difficulties in providing a sufficient number of outpatient appointments, underscoring the burden on high-volume centers.

Participants emphasized the role that ECCO may play in overcoming the gaps between desired QoC and real-world practice. Key suggestions included supporting especially national and international educational programs, developing position papers and guidelines, and promoting the UR-CARE registry. The registry, in particular, emerged as a valuable tool for benchmarking and fostering collaboration, especially for institutions managing high patient volumes. National educational programs in collaboration with ECCO should involve national IBD groups in order to identify and tailor the most effective educational strategies to improve and maintain QoC taking into account local barriers. Position papers and guidelines, on the other hand, should also take into account the real-world situation, in order to adapt recommendations, especially when supporting evidence is lacking, to meet challenges at the local level, especially in high-volume centers.

This study has strengths and limitations. This is the first large-scale project involving several institutions across

Europe, which investigates gaps between recommendations and real-world practice in the management of patients with IBD. Despite the strong effort to reach as many institutions as possible, some of them might have been missed because they are not affiliated to ECCO; moreover, our analysis is based on responses by the participants, thus exposed to possible biases, which were not verified by an auditing process. This main limitation was partially overcome by explaining responders that their contribution was not intended to certify good QoC, but to identify and be supported by ECCO to improve QoC.

ECCO is currently working on educational initiatives to improve QoC in countries, based on this survey. The next projects are to extend this survey outside Europe, and, in a 3-year period, to repeat the survey in the same units, to investigate whether some aspects of QoC have been improved over time. This project did not involve patients directly, but ECCO is planning with the partner patients' association (European Federation of Crohn's and Colitis Associations, EFCCA) to develop a collaboration focused on the patients' side.

5. Conclusion

The E-QUALITY survey identified some important gaps between the desired QoC standards and real-world practice. This provides a clear basis to promote or to improve existing ECCO initiatives more tailored to the differences and challenges across Europe.

Acknowledgments

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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; and all authors approved the final version of the manuscript.

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Conflicts of interests

G.F. served as a consultant and Advisory Board member for Takeda, Abbvie, Janssen, Pfizer, Celltrion, Sandoz, Ferring, Galapagos, Alfasigma, STADA, Eli Lilly; A.W. received grants from AbbVie, BMS, Buhlmann, Helmsley Trust, Janssen, Lilly, Pfizer, Takeda, and Norman Collisson Foundation, consultancy fees from AbbVie, Buhlmann, Falk, Ferring, Janssen, Lilly, Pfizer, Takeda, and speaker fee from AbbVie, Falk, Ferring, Janssen, Lilly; Pfizer, Shire, Takeda; M.B.d.A. 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, Adacyte and Vifor Pharma; J.B. 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; A.D. received consultancy fees from AbbVie, Amgen, Arena Pharmaceuticals, Biogen, Boehringer Ingelheim, Bristol Myers Squibb/Celgene, CED Service GmbH, Celltrion, Dr Falk Foundation, Falk Foundation, Ferring Pharmaceuticals, Fresenius Kabi, Galapagos, Gilead, High5MD, Janssen, Lilly, Materia Prima, Medfyle, Med Today, MSD, Pfizer, Pharmacosmos, Roche/Genentech, Sandoz/Hexal, Streamed-up, Takeda, Tillotts, and other fees from Vifor Pharma, Abivax, AbbVie, Arena Pharmaceuticals, Bristol Myers Squibb/Celgene, Dr Falk Foundation, Galapagos, Gilead, Janssen, and Pfizer; D.D. received grants from MSD, and consultancy fees from Abbvie, Amgen, Biogen, Janssen, Krka, MSD, Pfizer, Takeda; M.F. received grants from AbbVie, Biogen, EG, Janssen, Pfizer, Takeda and Viatris, consultancy fees from AbbVie, AgomAb Therapeutics, Boehringer Ingelheim, Celgene, Celltrion, Eli Lilly, Janssen-Cilag, MRM Health, MSD, Pfizer, Takeda and ThermoFisher; L.G. received grants from Helmsley Charitable Trust, and consultancy fees from Abbvie, Takeda, Pfizer, Janssen, Galapagos, Altman; M.I. received grants from Pentax, Olympus, Ely Lilli, and consultancy fees from Pentax, Pfizer, Galapagos; K.K. received speaker fees from Abbvie, Genesis, Janssen, Pfizer, and consultancy or advisory board member fees from Janssen, Pfizer and Roche; J.K. received lecture fees from Pfizer, Janssen, and Lilly, and consulting fees from Roche, Pfizer, Gilead, Takeda, Abbvie, Celltrion, Galapagos, Janssen, Pfizer, Tillots, and Lilly; S.R. received speaker and/or advisory board member fees from AbbVie, Janssen, Takeda, Bristol Myers Squibb, Sandoz, Vifor, Dr Falk, iQone, Lilly and UCB; D.S. received grants and lecture fees from Takeda; H.Y. received grants from Pfizer, ISF, and consultancy fees from AbbVie, Janssen, Pfizer, Takeda, and Bristol Myers Squibb, and Eli Lilly; the other authors declare no conflict of interests.

Data availability

Data cannot be shared for privacy reasons.

Supplementary material

Supplementary data are available online at *ECCO-JCC* online.

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