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Quality of care standards in inflammatory bowel diseases: a European Crohn's and Colitis Organisation (ECCO) position paper

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Abstract

The management of inflammatory bowel disease (IBD) is complex, and requires tight control of disease activity, close monitoring to avoid treatment side effects, healthcare professionals with expertise in IBD and an interdisciplinary, holistic approach. Despite various efforts to standardise structures, processes and outcomes[1-8], and due to the high variability at the local, national and international levels, there are still no clear definitions or outcome measures available to establish quality of care standards for IBD patients that are applicable in all contexts and all countries. For this reason, the European Crohn's and Colitis Organisation (ECCO) supported the construction of a list of criteria summarising current standards of care in IBD. The list comprises 111 quality standard points grouped into three main domains (structure n=31, process n=42, outcomes n=38) and is based on scientific evidence, interdisciplinary expert consensus and patient-oriented perspectives.

The list of proposed criteria is intended to represent the position of ECCO regarding the optimum quality of care that should be available to patients. Since healthcare systems and regulations vary considerably between countries, this list may require adaptation at local and national levels. It is recognised that not all these criteria that have been identified as optimal will be available in every unit. However, ECCO will continue its efforts to develop and coordinate projects and initiatives that will help to guarantee optimal quality of care for all IBD patients.

Keywords: European Crohn's Colitis Organisation, standards of care, quality of care, quality standards, structure, process, outcomes, inflammatory bowel disease, Crohn's disease, ulcerative colitis

Introduction

Inflammatory bowel disease (IBD), comprising Crohn's disease (CD) and ulcerative colitis (UC), is a chronic, typically progressive, life-long disease with increasing incidence and prevalence worldwide[9]. Due to insufficient control of mucosal inflammation, more than 50% of patients with CD develop complications that require surgery over time[10-12], and up to 20% of patients with UC undergo colectomy[13,14]. Up to 50% of patients experience at least one extra-intestinal manifestation of IBD[15]. Both CD and UC impair daily life and psychological well-being significantly, and both can lead to permanent disability[16-19].

The aetiology of IBD is recognised to be multifactorial resulting in heterogeneous clinical presentation and treatment response. As in most chronic diseases, lifestyle (e.g. diet, physical activity, smoking) and psychosocial factors (e.g. adherence, stress) influence the disease course. Accordingly, management of IBD is complex, and requires tight control of disease activity, close monitoring to avoid treatment side effects, healthcare professionals with expertise in IBD and an interdisciplinary, holistic approach[20]. Quality indicators can be classified as structure indicators, process indicators and outcome measures. Outcome measures involve traditional health care outcomes like hospitalisation, surgery and corticosteroid exposure, but patient-reported outcome and experience are also important as they reflect patient perspective on the quality of care. Despite various efforts to standardise structures, processes and outcomes[1-8], and due to high variability at local, national and international levels, there are still no clear definitions or outcome measures available to establish quality of care standards for IBD patients that are applicable in all contexts and all countries.

In 2018, a systematic review of quality of care standards in IBD was conducted, and described available structure, process, and outcome indicators that can serve as a basis to construct a minimum set of indicators for the assessment and measurement of quality of care for IBD patients[20]. Against this background, the European Crohn's and Colitis Organisation (ECCO) took the initiative to support the construction of a list of criteria designed to summarise optimal current standards of care in IBD. The list is based on scientific evidence, interdisciplinary expert consensus and patient-oriented perspectives and is aligned with ECCO Guidelines. It is recognised that few centres woll meet all criteria at the current time and one purpose of this position statement is to improve standards across institutions and to be a tool when negotiating with governments. It is not intended as a basis for certification or accreditation nor to send a message of exclusivity.

Methods

A systematic review, which some members of ECCO conducted independently[9], facilitated the development of a list of quality standard points (Tables 1-5) grouped under the following three domains:

- Structure (S)
- Process (P)
- Outcomes (O)

A panel of experts in the field of IBD (gastroenterologists, nurses, paediatricians, pathologists, radiologists, surgeons, pharmacologists) was selected after an open call to all ECCO members and committees. Four representatives of the European Federation of Crohn's and Colitis Associations (EFCCA), a patient advocacy organisation, were invited and included. Supplementary Table 1 shows the final list of panellists.

A Delphi-style process was performed among the panellists to rate the importance of each quality standard point on a three-point scale, defined as follows:

a) *Essential*, i.e. a criterion of critical importance that must be satisfied for a unit to be considered adequate for the management of IBD patients

b) *Desirable*, i.e. a criterion that is above the minimum required standards for management of IBD patients and might be considered important

c) *Not important,* i.e. a criterion that would ideally be met but is of limited or very limited importance

For the first stage, all panellists were provided with the list of quality standard points and their associated descriptions and were asked to rate each on a scale from 1 to 9 using an online form. Scores from 7 to 9 indicated an "essential" quality standard point, scores from 4 to 6 a "desirable but not essential" quality standard point and scores from 1 to 3 a "not important" quality standard point. Panellists were blinded to each other's votes. Responses were analysed using descriptive statistics; the importance of each quality standard point was assessed using the median score, and agreement was calculated as the percentage of panellists giving a compatible score (e.g. for "essential", the percentage of panellists giving a 7–9 rating).

The required threshold for agreement was set in advance at 80%. Quality standard points with higher than 80% agreement were not discussed further, while those that failed to reach this threshold were passed to the second stage. The quality standard points were discussed in depth by panellists at a face-to-face meeting at the ECCO Congress in Copenhagen in March 2019, with the potential to modify or amend them or their associated description. This meeting was followed by up to two rounds of online voting (with further discussions between voting if required), during which participants again ranked the quality standard points on the above three-point scale. If less than 80% agreement was achieved on any given importance level, the quality standard point was rated as "desirable" if the total percentage of

panellists who gave either a “desirable” or an “essential” rating exceeded 80%. If this threshold was not reached (i.e. if more than 20% of panellists gave a “not important” rating), the quality standard point was rated “not important”.

As there was insufficient time to discuss all second-stage quality standard points during the face-to-face meeting, the second stage was performed again online for the remaining quality standard points. Panellists were asked to provide detailed feedback on each remaining quality standard point (in free text) using a web form. Their responses for each quality standard point were compiled in an anonymous summary and provided to all panellists, who then again ranked the quality standard points online on a scale from 1 to 9. Again, if less than 80% agreement was achieved on an individual importance level, the quality standard point was ranked as “desirable” if more than 80% of panellists ranked it as either “desirable” or “essential”; otherwise it was ranked as “not important”. Details of the two voting rounds are shown in Supplementary Table 2.

In order to understand whether these quality standard points could be reliable and applicable to IBD Units in different ECCO countries, we asked the ECCO National Representatives to provide feedback and suggestions, and to indicate which quality standard points are currently available in their own Units by a checklist during the Council of National Representatives held in Barcelona on Sep 19th, 2019 (data not shown). Based on the discussion and the received feedback, some statements received major changes that underwent a new online voting session to approve these changes. These changes were near unanimously approved by the panellists. None of the quality standard points were considered as “not important” by the Consensus panel.

Results

STRUCTURE

The IBD core team

Both UC and CD are complex gastrointestinal diseases that impact significantly on patients' lives. Patients with IBD need not only specific diagnosis, monitoring and therapies, but also education, counselling, physical and emotional support and a direct link with the referral IBD unit, which is a team of healthcare professionals who has experience and competence to provide care to IBD patients. These tasks should be approached in an interdisciplinary manner by a core team including at least one specialist physician and one nurse.

The experience of a non-specialist physician may be insufficient to manage IBD patients adequately. Therefore, **presence of at least one trained physician with experience in IBD is necessary**[16]. Nurses play a key role in IBD management, by sharing with physicians their knowledge of monitoring and administering therapies and by providing education, support, counselling and advocacy to patients[21]. Although studies[22-25] have suggested cost effectiveness and enhanced patient care in centres with designated IBD nursing roles, limitations and poor understanding of the role and its potential persist in various countries and need to be overcome and clarified in an international context.

Interdisciplinary structure

Since patients with IBD usually require an interdisciplinary approach. **An IBD unit should work in the context of collaboration among a broad team of specialists dedicated to and/or expert in IBD,** often known as the multidisciplinary team (MDT). When appropriate expertise is not available in the same department or hospital, the IBD unit should provide patients with clear pathways of referral within a network of specialists/hospitals that are easily accessible and willing and able to share decisions and care. However, **at least one gastroenterologist/endoscopist, nurse, radiologist, pathologist and surgeon dedicated to IBD should be available to the hospital to ensure proper diagnosis and management**. The presence of a referral pathway to a surgeon with expertise in complex IBD procedures such as pouch surgery is essential for patients with severe and/or complicated disease. Likewise, a referral pathway for a stoma management specialist is also essential. Since IBD may cause nutritional deficiencies, malnutrition and malabsorption, **collaboration with a dietitian is required**. When these specialists are not available, the team should include a healthcare professional who understands nutritional aspects of IBD management.

Not all IBD units offer both paediatric and adult care. However, good transition from adolescent to adult care is essential for the future management of IBD[26]. **The IBD interdisciplinary team should provide transition clinics** or, if this is not possible, **should have a clear referral or transition pathway** within a network of other hospitals that have paediatricians with expertise in IBD.

Although not essential according to the current consensus, collaboration with at least one psychologist who manages complex cases, and with at least one pharmacist/pharmacologist/healthcare professional educated in pharmacology who can advise on the correct use of medications (dosage, interactions, drug stability, etc.), will add value and excellence to the quality of care.

For those patients who suffer from IBD-related extra-intestinal manifestations, associated comorbidities or side effects of IBD drugs, **availability of a dedicated specialist** in the same hospital or within a network of hospitals and management of these challenges **in close collaboration with the IBD team** are essential[15].

IBD unit facilities

Patients with IBD often need to be in close contact with the reference IBD unit, especially during disease flares. Moreover, the necessary monitoring of disease activity and progression[27,28] and the possible need for parenteral therapies require the availability of certain facilities within the IBD unit. The IBD unit should have **infusion facilities for parenteral drugs** and should be integrated into a hospital, or into a network of hospitals, **with emergency department and inpatient services**. The unit should provide a **helpline for patients** and have **sufficient number of IBD outpatient appointments available per week**. This number depends on the total number of patients followed up in each unit. There should be a patient registry including all IBD patients.

Coordination of IBD unit activities

Because the interdisciplinary approach requires co-ordination of team tasks and clear pathways with an appropriate structure, a lead for the service who acts as a working group leader is important. Although general guidelines for IBD management appear regularly, the development of in-house guidelines by each department, adapting the general quality standard points to the local context, is essential. The quality of care provided in the unit/department should be measured by appropriate quality indicators capable of identifying local values and limitations.

PROCESS

Diagnosis of IBD

Early recognition and diagnosis of IBD[29] and prompt management of disease flares and complications are essential[9]. IBD units should develop a **mutually convenient system with GPs**, **emergency wards and other specialists** that allows the IBD unit to take charge of newly diagnosed patients or patients with acute flares and/or complications and to offer specialised pathways of care. The IBD unit should offer **active management of appointments, facilities for diagnosis and monitoring, and close collaboration and ancillary care within the interdisciplinary network**. The diagnosis and monitoring processes for IBD patients should include **full colonoscopy with ileal examination** in all cases of suspected new IBD together with an **adequate number of biopsies** from

multiple sites[30-32]. The integration of **endoscopic findings with imaging techniques** for CD is essential (at least two different imaging techniques among computerised tomography, magnetic resonance enterography and bowel ultrasound should be available in IBD departments).

Monitoring of IBD

Regular monitoring should be available[27,28] and, when possible and feasible, alternative ways of regular and tight monitoring (i.e. virtual clinics) may be of value[33-38]. Therapeutic strategies should be supported by a **full assessment and confirmation of disease activity**. Patients at higher risk of colonic cancer should be offered a **dysplasia screening program** with high-definition endoscopy, and those **who are hospitalised for severe flares** or require surgery **should be managed jointly between the IBD core team and the surgeon** to ensure proper timing and preparation for surgery.

Counselling and patient education

Patients who require immunosuppressive therapy should be informed about the **benefits and risks of therapy** and should undergo **appropriate screening to prevent opportunistic infections**. **Adequate counselling about prevention** of opportunistic infections (i.e. vaccinations, prophylaxis, appropriate behaviour in cases of increased community risks)[39] and **regular monitoring of side effects** are necessary. The **use of steroids** as a long-term or frequent therapy should be avoided.

Counselling for women about the **appropriate timing and management of IBD during pregnancy** should be available. Generally, the communication with patients should encourage **active patient involvement**, with mechanisms for **two-way feedback** and with the **support of educational material and activities in partnership with patients' associations**.

OUTCOMES

Measuring the quality of care in IBD is challenging. Generally, assessment of the quality of care should reflect the degree of adherence of patient care pathways and measures to currently available guidelines. Accessible documentation of the processes of an IBD unit is essential for measurement of quality outcomes and for internal audits that can help improve the overall quality of care.

Prompt and easy access by patients to a physician of the IBD unit whenever necessary is considered essential for the adequate management of IBD patients. To ensure optimal continuity of care within the core and interdisciplinary teams, **the IBD unit should record all the information regarding each patient's individual disease characteristics**, such as IBD type, location, extent, activity and severity, using validated or widely used systems where possible (i.e. activity scores, classifications). The **processes to prevent and rule out infections** in case of disease flares

or before starting therapies in those who are at risk of opportunistic infections, and the **strategies for minimising other relevant side effects**, should be documented in patient files, at least in a brief, easy-to-understand form. Therefore, quality indicators include **adequate assessment of disease activity, disease severity and complications**; **documentation of preventive strategies adopted by the IBD team**, both for therapies and for the prevention of postoperative recurrence; and **regular and complete assessment of possible IBD-related health problems** such as malnutrition, anaemia and vitamin deficit. Other important strategies to prevent poor outcomes, such as **smoking cessation, adherence to therapies or vaccinations or control of the exposure time to steroids,** require documentation in patient files. Although not essential, measuring the proportion of patients with IBD-related impairment of quality of life, social activities and working activities can be of additional value.

There are no validated cut-offs for hospitalisation and surgery outcomes, although the **rates of mortality, readmission to hospital and complications related to surgical or medical procedures** represent a reasonable and widely accepted quality measure across countries.

DISCUSSION

The definition of quality of care standards is not well established, and the approach and definitions depend partly on the field of medicine to which the standards apply[20]. A recent definition is "that which a minimally competent physician in the same field would do under similar circumstances"[40]. Therefore, new approaches may be useful. An attempt to achieve a wide consensus among healthcare professionals and patients, with a view to producing and defining quality indicators, is one approach that seems particularly appropriate.

As in previous exercises for similar conditions and based on our systematic literature research[9], we set up, discussed and agreed a list of criteria that summarise the minimum quality of care for IBD patients. Healthcare professionals and patients agree that interdisciplinary management of IBD is essential, given that IBD involves several body systems and impacts greatly on mental well-being and daily life. Since IBD is relatively uncommon, the presence of healthcare professionals (physicians, surgeons, nurses, other specialists) with expertise in IBD is essential if the team is to address all the possible challenges related to the IBD course. The proactive involvement of patients (especially through patients' associations) also plays a very important role in achieving therapeutic goals and improving quality of care.

Every IBD unit/department should ideally offer the current highest standards of knowledge and facilities, as well as clear and dedicated pathways. Where not all facilities are available, the IBD unit should provide a network of units/hospitals that can share the patient's care. From diagnosis to hospitalisation and surgery, patients should have easy access to physicians and diagnostic tools such as endoscopy and imaging as well as being able to receive parenteral

drugs or to be hospitalised in the same unit/department. Regular monitoring is necessary and, whenever possible, should be patient friendly (e.g. remote monitoring, virtual clinics where appropriate). Moreover, there should be clear processes to increase the benefits of therapeutic strategies (e.g. smoking cessation programmes) and minimise the risk of therapies (e.g. regular blood testing for toxicity and clear patient information about risk factors and preventive strategies such as vaccinations).

Finally, the performance of an IBD service should be as measurable as possible. All disease characteristics and the relevant data on disease course should be documented. Also, the unit's processes should be documented whenever possible. This should allow a continuous audit trail and facilitate improvement of quality of care, and may allow adaptation and alteration of workflows depending on the site-specific circumstances. The presence of clear quality of care standards may also help patients in selecting their referral centre based on their own needs.

More generally, the standards identified and qualified as essential or desirable by our multidisciplinary and multinational group reflect the requirements that all IBD units across Europe should meet in order to guarantee optimal quality of care for all IBD patients.

ECCO Quality of Care Standards

Based on the above considerations, we believe that we can state that the essential and desirable criteria listed in Tables 1-5 define the minimum standards of care that should be available to IBD patients.

Final considerations

The list of proposed criteria is intended to be the position of ECCO regarding the quality of care that should be available to patients. It does not constitute a guideline. Since healthcare systems and regulations vary considerably between countries, this list may require adaptation at local and national levels. However, ECCO will continue its efforts to develop and coordinate projects and initiatives that will help to guarantee the best quality of care for all IBD patients.

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Conflicts of interest

ECCO has diligently maintained a disclosure policy of potential conflicts of interests (CoI). The CoI declaration is based on a form used by the International Committee of Medical Journal Editors (ICMJE). The CoI disclosures are stored at the ECCO Office and the editorial office of JCC and are also open to public scrutiny on the ECCO Website (https://www.ecco-ibd.eu/about-ecco/ecco-disclosures.html), providing a comprehensive overview of potential conflicts of interest of authors.

Authors' contribution

Gionata Fiorino and Javier P. Gisbert initiated and coordinated the project and drafted the list of quality standard points and the final manuscript; Theodore Lytras contributed as a methodologist in the project; Lisa Younge, Catarina Fidalgo, Sofie Coenen, Maria Chaparro and Mariangela Allocca supported the coordinators in the project,

performed the systematic review of the literature and helped to draft the list of quality standard points; all the authors participated in the Consensus meeting and voted on the quality standard points; all the authors approved the manuscript; the ECCO Governing Board critically reviewed and approved the manuscript.

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Table 1. Quality of care standards: IBD Unit			
Quality standard point[a]	**Definition (if any)**	**Importance[b]**	**Agreement (%)**
S. Structure			
S1.1 An IBD unit provides an interdisciplinary approach to the patient		Essential	100
S1.2 A structured interdisciplinary team for IBD has: **S1.2.1 an identified specialist**		Essential	96
S1.2.2 an identified nurse	*Requires the presence of at least one nurse trained in IBD care, with agreed arrangements to cover in his/her absence (e.g. a backup nurse)*	Essential	82
S1.2.3 an identified surgeon and clear referral pathway for complex IBD surgery such as ileo-anal pouch		Essential	96
S1.2.4 an identified pathologist	*Requires the presence (or a link to a pathologist in another institution for second opinions) of at least one pathologist who is the reference person for IBD*	Essential	100
S1.2.5 an identified radiologist		Essential	89
S1.2.6 an identified dietitian/nutritionist or a clear pathway for referral	*Requires the presence (or a link to a* identified *dietitian/nutritionist in another institution) of at least one dietitian/nutritionist, or a healthcare professional educated in nutrition, who is the reference person for IBD*	Essential	91
S1.2.7 an identified stoma management specialist or a clear pathway for referral		Essential	100
S1.2.8 an identified endoscopist		Essential	100
S1.2.9 an identified psychologist or a clear pathway for referral	*Requires the presence of (or referral to) at least one psychologist who is the reference person for IBD*	Desirable	96
S1.2.10 a link to a pharmacist or a healthcare professional educated in pharmacology		Desirable	96
S1.3 At least one member of the MDT provides patient education, counselling, emotional support, liaison and continuity		Essential	100
S1.4 An IBD unit provides access to other appropriate medical specialties	*The unit provides in-house or a network of* identified *specialists (e.g. rheumatologists, dermatologists, infectious disease specialists) to manage specific situations related to IBD in a timely manner.*	Essential	100
S1.5 An IBD Unit has a named lead for the service	*A reference person who coordinates all the activities of the IBD Unit*	Desirable	100
S1.6 An IBD unit develops and updates in-house departmental guidelines		Essential	100
S1.7 An IBD unit develops and updates quality indicators		Desirable	100
S1.8 An IBD unit provides a contact-line for the patient	*Telephone, email and portal, at least on working days and during working hours*	Essential	95

S1.9 An IBD unit has outpatient facilities where drugs can be administered intravenously		Essential	86
S1.10 An IBD unit is integrated with a hospital with an emergency department		Essential	81
S1.11 An IBD unit is integrated in a department that has hospitalisation facilities		Essential	94
S1.12 An IBD unit has a patient registry		Essential	100
S1.13 An IBD unit provides a sufficient number of outpatient appointments to meet demand		Essential	82
S1.14 An IBD unit establishes, records and discusses the individual treatment plan with every patient		Essential	100
P. Process			
P1.1 An IBD unit prioritizes triage and urgent care for patients with a recent diagnosis or a severe flare of IBD	*This circuit should be initiated by telephone contact with a member of the IBD unit (available from Monday to Friday). IBD nurse/doctor will take care of triage and offers the possibility of urgent outpatient consultation when there is a presumption of flare/complication/recent diagnosis.* *Specific protocols for IBD patients admitted to the ER department are available.*	Essential	84
P1.2 An IBD unit develops and provides identified care pathways for IBD patients	*Pathways for: first symptoms, diagnosis, initiation of treatment, maintenance, management of flares, continuous patient care and surgery*	Essential	94
P1.3 An IBD unit holds regular MDT meetings and formally records the conclusions for each patient	*The output of the meeting is part of the patient's medical record. Participants have protected time* identified *to their attendance at the meeting.*	Essential	90
P1.4 An IBD unit provides routine follow-up and access for early recognition of flares and disease worsening		Essential	89
P1.5 An IBD unit provides timely surgery and post-operative follow up		Essential	86
P1.6 An IBD unit provides administrative support and arrangement of appointments		Essential	82
P1.7 A transition clinic is available	*Definition: In centres looking after IBD patients in transition from paediatric to adult care, a transition clinic or a clear pathway for referral with a direct link to adult care is available. IBD centres for adults have facilitated pathways for transition*	Essential	83
P1.8 An IBD unit offers remote follow-up	*Remote follow-up including any kind of facility (phone/email/web portal, etc.)*	Desirable	90
P1.9 An IBD unit provides virtual clinics	*Incorporation of patient self-management whereby patients share their state of health with the health care team*	Desirable	88
O. Outcomes			
O1.1 Timely access to care	*The waiting list for an appointment at the IBD unit for a follow-up visit allows the patient to be seen within*	Essential	89

	the appropriate time.		
O1.2 Ileo-anal pouch surgery is only conducted in units performing at least 10 of these operations per year		Desirable	100

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[b] In rating the importance of a quality standard point, "essential" represents a criterion of critical importance that must be satisfied for a unit to be considered adequate for the management of IBD patients while "desirable" represents a criterion that is above the minimum required standards for management of IBD patients and might be considered important.

Table 2. Quality of care standards: Assessment and Treatment			
Quality standard point[a]	**Definition (if any)**	**Importance[b]**	**Agreement (%)**
P. Process			
P2.1 When a patient is diagnosed with IBD, the extent of the disease is assessed		Essential	96
P2.2 Disease activity is assessed after starting treatment to determine adequate control, using appropriate combinations of clinical evaluation, endoscopy, radiology and biological assessments in both CD and UC patients.	*After a treatment strategy is initiated, the treatment success needs to be evaluated in terms of symptom control and resolution of inflammation/complications (or at least a cessation of disease progression). Adequate time is consistent with current guidelines, time to onset of action of prescribed drug(s), and patients' needs and characteristics.*	Essential	89
P2.3 There is access to deep sedation during endoscopy for selected patients	*Deep sedation is based on intravenous propofol administrated by a specialist and should be of a level in which patients may perform a purposeful response to verbal or light tactile stimulation without need for intubation*	Essential	84
P2.4 Scores/indexes are used for endoscopic assessment of disease activity and severity	*Detailed description of lesions is present in all endoscopic reports. Whenever possible, validated scores or commonly used scores are calculated, and the final score is reported.*	Desirable	100
P2.5 During colonoscopy, the ileum should be examined in IBD patients		Essential	93
P2.6 The endoscopist takes an adequate number of biopsies in any IBD patient		Essential	89
P2.7 Enteroscopy (any technique) is done used for diagnosing and monitoring patients with jejunal and - proximal ileal disease	*Enteroscopy (any technique) is available, or there is a clear referral pathway in other units/hospitals, in cases of suspected small bowel CD, if imaging techniques are doubtful or negative in the presence of a strong clinical suspicion.*	Desirable	94
P2.9 The pathologist attempts to give a definite diagnosis of IBD on intestinal biopsies, and to classify as UC or CD where possible		Desirable	90
P2.10 At least, two imaging techniques (MR or CT enterography or bowel ultrasound) are available to be used to assess disease activity and complications		Essential	89
P2.11 Regular monitoring is performed for patients in remission		Essential	89
P2.12 In patients with symptoms despite IBD treatment, activity is evaluated at least by biomarkers (when baseline biomarkers are available), colonoscopy (especially when biomarkers are doubtful or positive)	*Disease activity is assessed by combining symptoms/patients' reported outcomes with objective signs of inflammation. Every therapeutic decision is based on this combination.*	Essential	100

and/or radiology to guide therapeutic decisions			
P2.13 High-definition colonoscopy is the first choice for colon cancer surveillance		Essential	94
P2.14 Patients receiving more than 2 cycles of corticosteroids per year are considered for steroid-sparing regimens		Essential	86
P2.15 Patients should not receive systemic corticosteroids more than 20 mg/day prednisolone or equivalent for greater than 16 weeks		Essential	86
P2.16 Patients are not exposed to any dose of systemic corticosteroids for more than 9 months per year		Essential	100
P2.17 Patients with small bowel disease and/or previous ileal resection are regularly tested for vitamin B12 and folic acid and prescribed adequate replacement if needed		Essential	94
P2.18 Female patients continue maintenance therapy during pregnancy as long as possible to prevent relapses		Essential	82
P2.19 Therapeutic drug monitoring (reactive or proactive) is routinely used to optimise/monitor therapies	*Therapeutic drug monitoring for serum levels and, in the case of monoclonal antibodies, anti-drug antibodies, is routinely done to allow optimisation/continuation of therapy.*	Desirable	100
P2.20 Time-bound step-up algorithm for disease management is followed for acute severe colitis		Essential	82
P2.21 Venous thromboprophylaxis is prescribed in all IBD patients while hospitalised	*The risk of thromboembolic complications is increased in patients with IBD, mainly during hospitalisations. In fact, they constitute one of the main causes of mortality in IBD. Therefore, patients hospitalised for IBD should receive prophylaxis with anticoagulant therapy. Patients who are hospitalised for the treatment of acute IBD (flare) should be offered pharmacological prophylaxis against venous thromboembolism (or mechanical prophylaxis when pharmacological prophylaxis is contraindicated).*	Essential	89
P2.22 Patients hospitalised for acute severe UC are followed on a multidisciplinary basis	*At least, by a gastroenterologist, a nurse and a colorectal surgeon*	Essential	89
P2.23 A fast-track recovery programme is applied for all patients undergoing IBD-related surgery		Desirable	100
P2.24 A laparoscopic approach (when possible) combined with an enhanced recovery pathway is applied		Essential	89
P2.25 Nutritional status, iron, vitamin B12 and folate are assessed once a year and during and after a flare	*Patients are assessed and monitored at least for iron status, anaemia, albumin, and vitamins D and B12. The timing of regular monitoring depends on guidelines,*	Essential	83

	individual patients' characteristics, risk factors for malnutrition/malabsorption and response to replacement therapies.		
O. Outcomes			
O2.1 All IBD patients with risk factors for metabolic bone disease, including prolonged corticosteroid use, are assessed for bone loss		Essential	82
O2.2 Patient receiving methotrexate also receive folic acid supplements		Essential	89
O2.3 CD patients who have undergone resection undergo colonoscopy to assess for disease recurrence within 6-12 months	*Recurrence of CD after surgery is very frequent, even when the patient is taking preventive treatment. Endoscopic assessment 6-12 months after surgery is recommended to guide treatment optimisation.*	Essential	89
O2.4 Mental health and well-being are assessed and advice or referral to a psychologist is provided for those patients in whom they are impaired	*Mental health and well-being are part of the clinical evaluation, and any case of psychological distress is directly managed or referred to a reference specialist according to the patient's needs.*	Desirable	100
O2.5 In patients with severe flare-up of UC not responding to intravenous corticosteroids, treatment with either cyclosporine or infliximab is initiated within 7 days	*If there is an indication for a rescue therapy in severe UC, any medical therapy is started within 7 days from the first i.v. systemic steroid dose.*	Essential	89
O2.6 Patients with CD receive treatment to prevent recurrence after surgery according to risk factors	*The recurrence of CD after surgery is the rule in the absence of a preventive treatment. Patients should receive the appropriate treatment considering their risk factors for postsurgical recurrence and should receive treatment according to updated recommendations.*	Essential	89
O2.7 In IBD patients undergoing elective surgery, the rate of severe morbidity requiring ICU admission is lower than 5%		Essential	86
O2.8 Mortality due to elective surgery is less than 2%		Essential	89
O2.9 The rate of temporary ileostomy after elective ileocecal resection is lower than 20%			

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Table 3. Quality of care standards: Infections

Quality standard point[a]	Definition (if any)	Importance[b]	Agreement (%)
P. Process			
P3.1 Screening for specific undiagnosed or latent infections (according to the current guidelines) is performed before starting any immunomodulator	*Immunomodulator means any drug that may alter the normal immune status, including corticosteroids, IMM, biologics and small molecules*	Essential	96
P3.2 Patients with positive screening for latent infections (e.g. TBC or HBV) undergo adequate specific prophylaxis prior to commencing immunomodulators		Essential	96
P3.3 IBD patients under triple immunosuppression receive prophylaxis for *Pneumocystis* sp. infection		Essential	82
O. Outcomes			
O3.1 Patients starting or receiving any immunosuppressant treatment are screened for specific or undiagnosed latent infections and regularly advised on preventive strategies to adopt (including vaccinations) according to the current guidelines. These recommendations are reported in the patient files.		Essential	100
O3.2 In patients with UC or colonic CD and a severe flare-up refractory to treatment, rectal biopsies or CMV PCR are taken to rule out CMV infection.		Essential	93
O3.3 *Clostridium difficile* and other common intestinal infections are ruled out in every flare-up that presents as diarrhoea	*The term "common infections" includes any intestinal infection according to guideline recommendations, local epidemiology and individual risk factors.*	Essential	94
O3.4 Hospitalised IBD patients with diarrheal symptoms undergo testing for *Clostridium difficile*		Essential	89

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Table 4. Quality of care standards: Patient Registry			
Quality standard point[a]	**Definition (if any)**	**Importance[b]**	**Agreement (%)**
S. Structure			
S4.1 An IBD unit registers the defined minimum set of quality indicators and delivers data (anonymised) for benchmarking and practice variation assessment		Desirable	84
O. Outcomes			
O4.1 IBD type, anatomic location, activity and severity are documented		Essential	100
O4.2 The number of days per month/year lost from school/work attributable to IBD is measured		Desirable	93
O4.3 The number of days per year in the hospital attributable to IBD is measured		Desirable	89
O4.4 The number of emergency room visits per year for IBD is measured		Desirable	89
O4.5 The proportion of patients with malnutrition is measured	*The proportion of patients with malnutrition over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	89
O4.6 The proportion of patients with anaemia is measured	*The proportion of patients with anaemia over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	89
O4.7 The proportion of patients with fatigue is measured	*The proportion of patients with fatigue over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	89
O4.8 The proportion of patients with normal disease-targeted health-related quality of life is measured	*The proportion of patients with normal quality of life assessed by specific questionnaires over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	83
O4.9 The proportion of patients with night-time bowel movements or leakage is measured	*The proportion of patients with night-time bowel movements over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	83
O4.10 The proportion of patients with incontinence in the last month is measured	*The proportion of patients with incontinence over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	89
O4.11 Corticosteroid use (including the proportion of patients with corticosteroid-free clinical remission for > 12 months) is measured	*The proportion of patients using steroids over the total number of patients in active follow-up is measured (or can be derived) at least once a year and recorded by the centre/institution.*	Desirable	89
O4.12 Corticosteroid use (excluding those diagnosed within the last 112	*The proportion of patients using corticosteroids over the total*	Desirable	89

days) is measured	*number of patients in active follow-up is measured (or can be derived) at least once a year and recorded by the centre/institution.*		
O4.13 The proportion of patients currently taking narcotic analgesics is measured	*The proportion of patients using narcotics over the total number of patients in active follow-up is measured (or can be derived) at least once a year and recorded by the centre/institution.*	Desirable	89
O4.14 Short-term non-elective readmission and reintervention rates after resection for IBD are measured	*Readmission for hospitalisation within 30 days after discharge from the Colorectal Surgery Department*	Desirable	100
O4.15 Proportion of patients with normal quality of life is measured	*The proportion of patients with normal quality of life (measured with appropriate scores) over the total number of patients in active follow-up is measured (or can be derived) and recorded by the centre/institution.*	Desirable	89

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Table 5. Quality of care standards: Patient Education

Quality standard point[a]	Definition (if any)	Importance[b]	Agreement (%)
P. Process			
P5.1 An IBD unit provides educational leaflets written in easily understandable language, preferably in partnership with patient associations	*The unit should have a structured patient support programme that includes: appropriate patient educational material, patient education delivery and follow-up.*	Essential	90
P5.2 An IBD unit provides patient involvement opportunities with clear mechanisms for two-way feedback	*May include newsletters, regular meetings between patients and IBD staff, etc.*	Essential	94
P5.3 Patients are advised on how to prevent opportunistic infections (according to the current guidelines) before starting any immunomodulator or in any case of increased risk	*Immunomodulator means any drug that may alter the normal immune status, including corticosteroids, IMM, biologics and small molecules. It includes also vaccinations. Cases of increased risk include travelling abroad, change in life habits, etc.*	Essential	93
P5.4 Patients are advised and educated on how to prevent any adverse event related to therapies		Essential	86
P5.5 Patients are advised on the risk of malignancies related to IBD and/or therapy and are regularly monitored		Essential	82
P5.6 Female patients are advised to plan pregnancy (whenever possible) after attainment of disease remission		Essential	86
O. Outcomes			
O5.1 CD patients are informed about the risks of smoking, cessation is recommended and support is provided for those wishing to quit		Essential	89
O5.2 The patient receives relevant and understandable information regarding benefits and risks before starting any medical therapy for IBD or surgery, and this is documented in clinical records		Essential	90

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