

Quality outcome measures project in IBD: a proof-of-concept benchmarking study in three Belgian IBD units

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Abstract

Introduction: Current treatment modalities in IBD allow us to render normal quality of life to most patients. Ideally, structured digital care pathways can be harmonised in order to measure (semi-) automatically key outcome quality indicators and compare between institutions.

Materials and methods: Key quality criteria were selected through a consensus process and aligned with the ICHOM quality criteria in IBD, including clinical parameters, PROMs, quality of life, health care utilisation and productivity.

Results: Measurements of the 11 selected key quality criteria were integrated in the structured care pathways of three IBD units. All patients received (at least) twice a year three questionnaires (PRO2 or SCCAI, ICHOM criteria and IBD Disk) through the electronic application to collect necessary information ahead of their planned outpatient clinic. In addition, interpretation of biomarkers was automated, and more difficult outcome indicators were manually added by the caregiver during the visit in anticipation of adaptations to or improvements of the electronic record. All information was collected centrally electronically in a structured way allowing benchmarking between the three centres, and stored for future retrospective research.

Conclusion: A (partially) automated benchmarking for measuring quality of care is feasible. It provides an objective assessment of IBD care, enables benchmarking between centres and facilitates quality improvements projects. (*Acta gastroenterol. belg.*, 2023, 86, 1-6).

Keywords: IBD care pathway, outcome quality indicators, benchmarking.

List of abbreviations: CD: Crohn's disease; IBD: Inflammatory Bowel Disease; IBD-U: IBD unclassified; ICHOM: International Committee Health Outcome Measures; PROMS: Patient Reported Outcome Measures; SCCAI: Simplified Clinical Colitis Activity Index; UC: Ulcerative colitis; VBHC: Value Based Health Care.

Introduction and aims

The current way of practising medicine in Belgium and in many other countries is still very traditional based on fee per (technical) acts and not based on quality and hence suboptimal, especially for patient with chronic diseases. Therapeutic modalities have dramatically improved with a shift in health care expenditure from hospitalisations and surgery to cost for medications (1). Due to these new opportunities many newly diagnosed young patients maintain a more than acceptable quality of life and can study, become professionally active, participate in sports and various social activities, raise a family etc...

Digital care pathways are becoming a popular tool to enable structured and optimised care delivery, monitoring,

and improved patient experience through better education and shared decision making, which continuously improves the quality of care (2,3). By standardisation of these pathways and agreement on key outcome indicators the quality of the care can be measured.

We hereby report on the feasibility of a value-based health care project in inflammatory bowel disease (IBD) through a collaborative effort between three non-academic regional dedicated IBD clinics. Our aim was to demonstrate that the quality of modern care delivered in a structured pathway for IBD patients can be measured on population level and benchmarked between hospitals, while individual care can be structured and optimised. To demonstrate this, we build a platform that automatically captures key outcome quality indicators for IBD care.

Materials and Methods

A task force encompassing the IBD units at Imelda Ziekenhuis Bonheiden, AZ Maria Middelaes Gent and AZ Delta Roeselare-Menen-Torhout, Awell (<https://www.awellhealth.com>), and Value Based Healthcare experts from Amgen (<https://amgen.be>) and Vintura (<https://www.vintura.com>) was formed to define outcome quality indicators in IBD and to set up an automated dashboard comparing these indicators between the different centres.

After review of the available relevant literature, two Delphi-like non-blinded review sessions were held with physicians and IBD nurses of the participating centres followed by a consensus meeting. This led to a selection of outcome indicators that could be measured and had the potential to improve the outcomes. The key quality criteria agreed upon were aligned with the ICHOM quality criteria in IBD (<https://www.ichom.org>) (4) and included clinical parameters and Patient Reported Outcome Measures (PROMs), a validated IBD quality of life tool (IBD disk) (5), health care utilisation and productivity.

Data were provided through different sources: (i) the patients (PRO's, IBD disk), (ii) the laboratory databases (haemoglobin, C-Reactive Protein, calprotectin), and (iii) the health-care providers who manually added emergency visits and surgery, development of cancer

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and serious infections. All patients consented for the use of the application to collect PROMS through Awell. In parallel, informed consent was obtained to use the UR-Care platform for retrospectively collecting baseline demographic data and key information on the disease that cannot be readily automatically collected from electronic records (e.g. Montreal classification, lines of treatments and dates of and reasons for starting and stopping).⁶ Ethical approval for collecting data prospectively and ensuing retrospective analysis was obtained at all participating institutions.

For the interpretations of the different dashboards, a few elements needed to be taken into account. The category “No answer/Geen antwoord” in the graphs means that the form from which the data were collected, was submitted without this field being filled in. As we have made all benchmark indicators required in the care pathways, the percentage of patients for this category will decrease over time. The answer “N/A” means the patient is in the care pathway but the form, from which the data is collected, has either not yet been activated in the pathway or has been last submitted more than a year ago. The benchmark indicators results are calculated with the following formula (Yes) / (Yes + No + No answer). Patients that have been in the care pathway for less than a year or did not submit any form in the last 12 months, were excluded from the results.

Results

From Jan 2019 to October 2022 a total of 1591 patients (39 % F ; 58 % CD %, 41% UC and 2 % IBD-U) were included in our feasibility study. Within the three participating hospitals, a structured care pathway was established over many years with the help of the IBD

Table 1. — Overview and definitions of benchmark indicators

– Proportion of patients in deep remission (defined as CRP and calprotectin below upper limit of normal)
– Proportion of patients in clinical remission (for CD PRO2 Individual score for stool frequency SF <= 3 and for abdominal pain <= 1 ; for UC rectal bleeding = 0 and stool frequency <=2)
– Proportion of patients with fatigue (if reported > 3 according to IBD Disk at least once in the 2 last reports)
– Proportion of patients with lower productivity due to IBD (if reported > 3 according to IBD Disk at least once in the 2 last reports)
– Proportion of patients using systemic steroids
– Proportion of patients on topical steroids
– Proportion of patients with anaemia (defined as a Hemoglobin < 12 g/dl in females and < 13 g/dl in males
– Proportion of patients with serious infections (defined as for which patients were admitted)
– Proportion of patients admitted to the hospital for IBD flare
– Proportion of patients with unscheduled or urgent surgery for IBD
– Proportion of patients that developed colorectal carcinoma

nurses. Using the Awell Health platform, this care pathway was automated and digitalised. The exact definitions and type of quality outcome indicators to measure are shown in Table 1. To collect this data, the ICHOM standard data set was measured and three IBD questionnaires (PRO2 for CD, SCCAI for UC and the IBD disk for all patients) were used.

All patients received an e-mail notification twice a year through their smartphones with a weblink to fill out these questionnaires (Gent, Roeselare), or were able to fill in the questionnaires before any visit to the outpatient clinic on a tablet in the waiting room (Bonheiden).

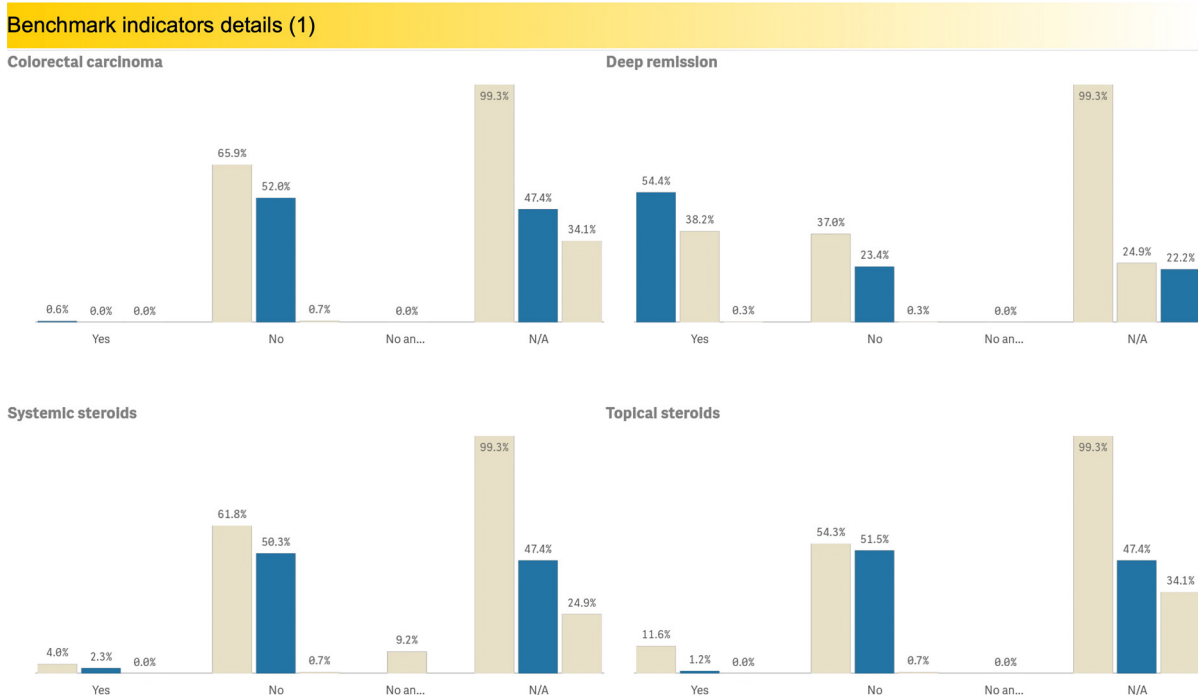


Figure 1. — Population dashboard for benchmarking: deep remission (clinical and biomarkers) and use of steroids (each bar representing a different hospital).

Benchmark indicators details (2)



Figure 2. — Population dashboard for benchmarking: serious infection, anemia and clinical remission (each bar representing a different hospital).

Benchmark indicators details (3)

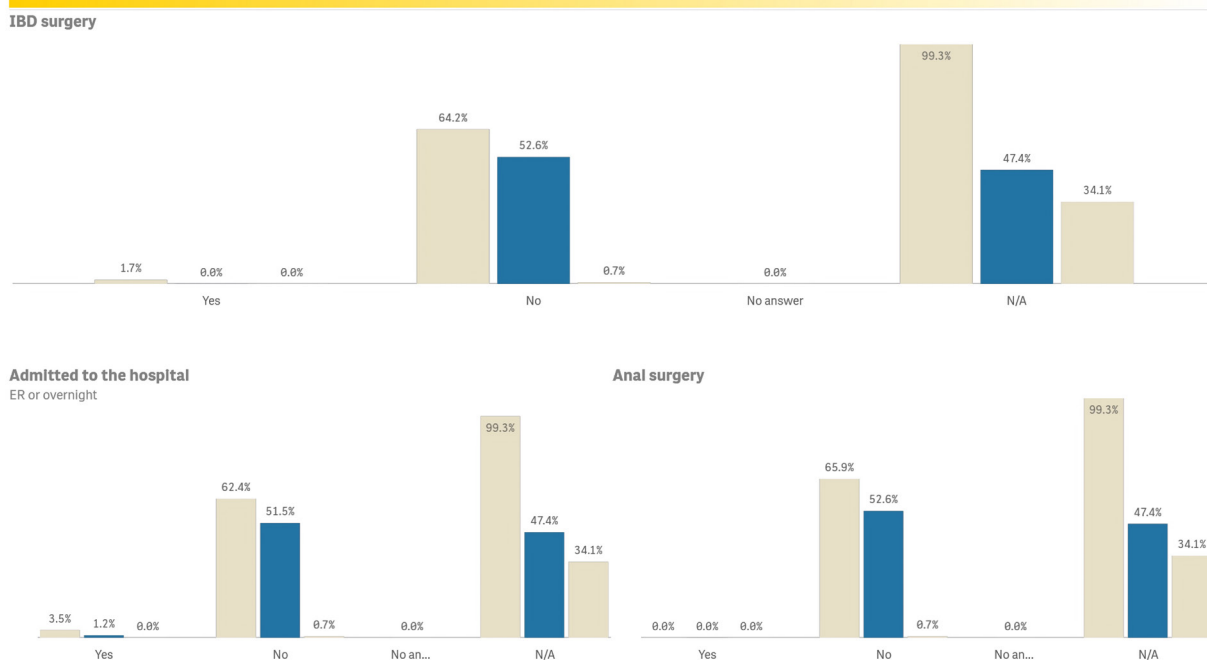


Figure 3. — Population dashboard for benchmarking: IBD surgery or admissions for IBD complications (each bar representing a different hospital).

Doing so, data on the various outcome indicators were available for health-care providers in all participating hospitals ahead of the planned outpatient visit. The data entered by the patient were transferred automatically in the electronic patient record, providing the IBD nurse or physician instantaneously all the necessary information

without need for routine questions and typing, writing, or dictating as was the case before. When patients reported specific problems or debilitating quality-of-life issues they had the option to flag if they wanted to discuss this further or requested specific help. In addition to the clinical information, patients were asked to perform

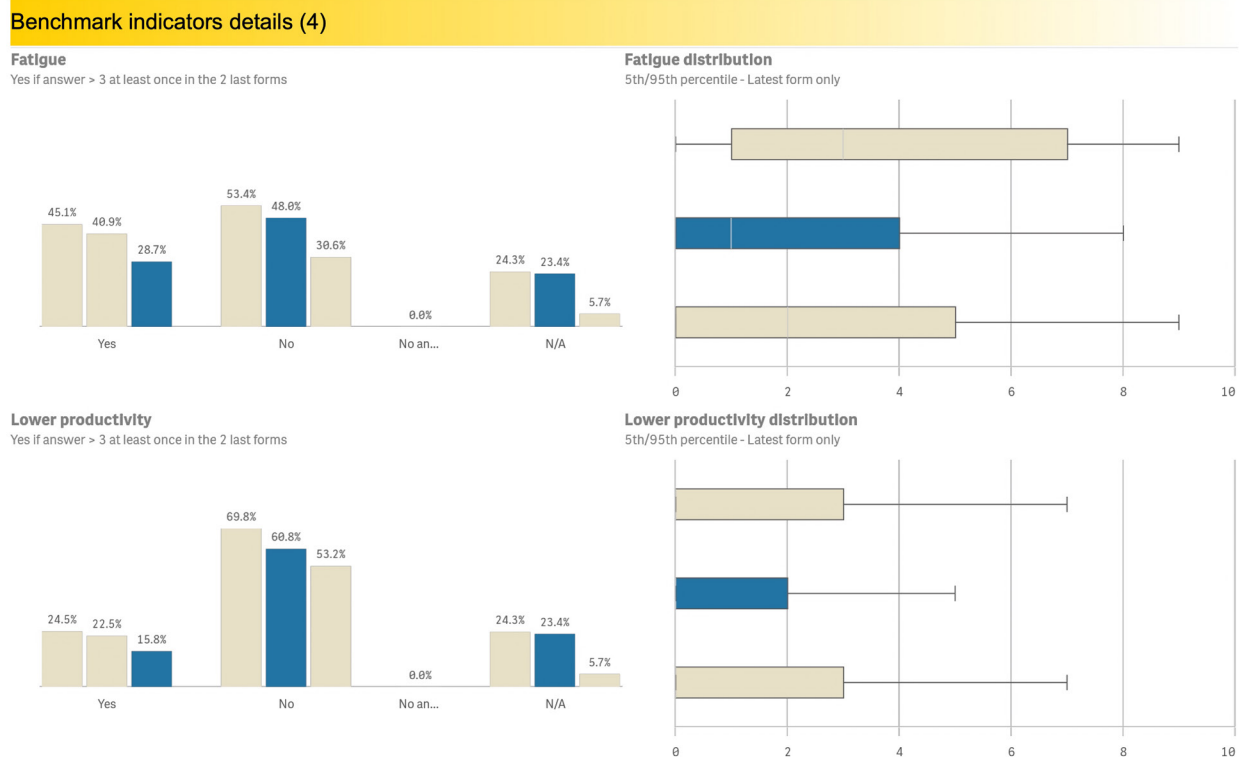


Figure 4. — Population dashboard for benchmarking: fatigue and productivity (each bar representing a different hospital).

laboratory tests and bring in stool samples ahead of the visit, to monitor biomarker evolution.

We give examples of the benchmarking showing differences between the hospitals for the different outcome indicators (Fig 1-4). As you can see the data are more complete when reported by the patients e.g. clinical remission, fatigue and productivity (Figure 2 and 4) versus those that have to be calculated through extraction from the laboratory data or those who require a manually input e.g. serious infection, admission, urgent surgery. (Figure 1 and 3)

The acceptance of the system by the patients was positive to very positive in > 80% of patients. Problems were encountered in a minority (< 10%) of patients for various reasons (fear of spamming, lack of smart phone, internet connection, language problems, mental health issues). After the initial set-up and time investments, physicians and IBD nurses in three centres clearly valued the system as it saves time in most patients and allows for a more tailored approach in patients that highlighted specific issues. Finally, being able to demonstrate the quality of care is stimulating and rewarding for the team.

Discussion

We hereby demonstrate that it is feasible to build an automated dashboard with quality indicators through a standardised care pathway. This facilitates efficient and holistic care delivery and enables collaboration and sharing best practices between hospitals.

The benefits of this system are obvious and include information to optimize individual treatment, give a

real time overview of the care delivery on a population level and understand and measure impact of certain interventions, being able to benchmark and start sharing knowledge between centres, partially share the work load and, finally a value-based review of the health care utilisation.

The set-up of the system was time consuming in the various centres, by joining efforts this could be reduced somewhat but the implementation remains very specific per centre because of the different electronic patient records and different informatic systems. However, as more and more patients signed up over time, we noticed a clear increase in productivity of the outpatient visits as the information became available in the chart, rendering visits for patients in remission very fast and efficient and liberating more time for those patients with specific issues to address. This digital care pathway enables also the option to start well documented remote visits via video-consultation, where the digital care pathway is the back bone for the correct interpretation of the status of the patient.

By measuring PROM's, the patient reports on a regular basis its subjective assessment of its conditions which is key for caregivers to understand and to measure. This can be automated by using appropriate app's or web-based tools that are currently recognised and in some disease areas supported by the health authorities.

In addition, next level of monitoring patients with IBD is tracking the long-term progression of the disease, and hereby trying to prevent the ensuing complications such as stenosis, fistulae and abscesses with need for surgery or development of dysplasia and cancer.

Supplement Table 2. — The subset of 19 quality measures with estimated potential for improvement

	<u>Medication</u>
1	Proportion of patients with IBD on systemic steroids for >3 months in the last 12 months
2	Proportion of patients with ulcerative colitis admitted with a flare that received intravenous steroids >7 days without surgery and without adding rescue treatment (a biologic, a small molecule or cyclosporin) in the last 12 months
3	Proportion of patients with IBD who received calcium and vitamin D supplements while on systemic corticosteroids in the last 12 months
4	Proportion of patients with IBD who received low molecular weight heparin prophylaxis while being hospitalised in the last 12 months
5	Proportion of patients starting infliximab that combined this with an immunomodulator (azathioprine, mercaptopurine, thioguanine, methotrexate)
	<u>Use of hospital services</u>
6	Proportion of patients with IBD requiring emergency room admission for IBD-related causes in the last 12 months
	<u>Post-intervention</u>
7	Proportion of patients with IBD having a documented endoscopic reassessment within 12 months after an ileocolonic resection in the last 12 months
8	Proportion of patients with IBD with readmission within 30 days after IBD-related surgery in the last 12 months
	<u>Infections</u>
9	Proportion of patients with IBD receiving pneumocystis jirovecii pneumonia prophylaxis while on triple immune suppression in the last 12 months
10	Proportion of patients with IBD under immunosuppressive therapy* that received an adequate pneumococci vaccination in the last 5 years
	<u>Follow-up</u>
11	Proportion of patients with IBD where body weight was measured at least once in the last 12 months
12	Proportion of patients with Crohn's disease having an endoscopic evaluation within 12±2 months after start of a new line of treatment in the last 12 months
13	Proportion of endoscopy reports of patients with IBD where an endoscopic activity score was used in the last 12 months
14	Proportion of patients with Crohn's disease that was actively smoking in the last 12 months
	<u>Disease activity</u>
15	Proportion of patients with IBD with steroid-free (systemic and topic) clinical remission in the last 12 months
	<u>Patient-reported outcome measurements</u>
16	Proportion of patients with IBD with at least one patient-reported outcome evaluation for symptoms (PRO2, SCCAI or equivalent instrument) in the last 12 months
17	Proportion of patients with IBD with normal health-related quality of life (total IBD Disk score <40 or equivalent) in the last 12 months
18	Proportion of patients with IBD who reported difficulty with productivity (IBD Disk education and work score ≥4 or equivalent) in the last 12 months
19	Proportion of patients with IBD who reported difficulty with energy (IBD Disk energy score ≥4 or equivalent) in the last 12 months

Finally, all collected information is stored in a structured time sensitive way providing a very valuable resource for potential future research. Despite the impressive improvements in IBD care, literature reports on measuring quality of care are particularly scarce (7-11).

During our process we encountered several challenges. Although IBD nurses and gastroenterologists are central in the IBD units, care is also delivered by general practitioners, emergency medicine, non-specialised gastroenterology colleagues that are not always aware of or aligned with the quality recommendations. Unfortunately, the regulatory authorities in Belgium are

currently providing the incentives by reimbursing procedures and complications instead of remote care or providing incentives for quality. IBD nurses that are central in this process are still not recognised nor reimbursed for their activities. Different hospitals have different IT-infrastructure and in particular adaptations to the hospital's electronic records are difficult and cumbersome. In anticipation of further adaptations to the electronic records some outcome indicators needed to be filled out by the care givers manually in the Awell system. Current GDPR regulations are strict and time consuming and individual informed consent is needed to collect routine clinical care data and to perform retrospective

analysis. Lastly, the system to collect PROM's sometimes disconnects or the motivation of patients drops, particular in patients in remission.

The current data have their limitations as some data collection is incomplete and the case mix differs among the different centres depending whether all patients were included or only patients on e.g. subcutaneous biologics. To be able to really benchmark the patient population, a detailed description is needed in terms of disease type, location/extent (Montreal classification), education level, smoking status, age at onset, co-morbidities, BMI etc.

The current initiative is now being replicated on a larger level in Belgium with a broader Delphi consensus process including not only gastroenterologists, IBD nurses but also patients, chief medical officers, surgeons and paediatrician's. In this effort, Marc Ferrante and Liselotte Fierens are joining under the umbrella of the 'Vlaams Ziekenhuis Netwerk KU-Leuven' (VZN KUL). This working group recently came to a larger set of suggested quality indicators (12) (Supplement Table 2).

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References

1. VAN LINSCHOTEN R.C.A., VISSER E., NIEHOT C.D., VAN DER WOUDE C.J., HAZELZET J.A., VAN NOORD D., WEST R.L. Systematic review: societal cost of illness of inflammatory bowel disease is increasing due to biologics and varies between continents. *Aliment Pharmacol Ther*; 2021;**54**:234-248.
2. BOSSUYT P., POUILLON L., BONNAUD G., DANESE S., PEYRIN-BIROULET L. E-health in inflammatory bowel diseases: more challenges than opportunities. *Dig Liver Dis*. 2017;**49**:1320-1326.
3. BOSSUYT P., HOEFKENS E., POUILLON L. Prime Time Was Yesterday for Patient-reported Outcomes in Daily Care of Patients With Inflammatory Bowel Diseases. *Clin Gastroenterol Hepatol* 2018;**16**:1839.
4. KIM A.H., ROBERTS C., FEAGAN B.G., BANERJEE R., BEMELMAN W., et al. Developing a Standard Set of Patient-Centred Outcomes for Inflammatory Bowel Disease – an International, Cross-disciplinary Consensus. *Journal of Crohn's and Colitis* 2018;**12**: 408-18.
5. GHOSH S., LOUIS E., BEAUGERIE L., BOSSUYT P., BOUGUEN G., et al. Development of the IBD Disk: A Visual Self-administered Tool for Assessing Disability in Inflammatory Bowel Diseases 2017;**23**:333-340.
6. BURISCH J., GISBERT J.P., SIEGMUND B., BETTENWORTH D., THOMSEN S.B., et al. Validation of the 'United Registries for Clinical Assessment and Research' [UR-CARE], a European Online Registry for Clinical Care and Research in Inflammatory Bowel Disease. *J Crohns Colitis* 2018;**12**:532-537.
7. AHMED Z., SARVEPALLI S., GARBER A., REGUEIRO M., RIZK MK. Value-Based Health Care in Inflammatory Bowel Disease. *Inflamm Bowel Dis* 2019;**26**:958-968.
8. BERRY S.K., SIEGEL C.A., MELMED G.Y. Quality Improvement Initiatives in Inflammatory Bowel Disease. *Curr Gastroenterol Rep* 2017;**19**:41.
9. EGBERG M.D., GULATI A.S., GELLAD Z.F., MELMED G.Y., KAPPELMAN M.D. Improving Quality in the Care of Patients with Inflammatory Bowel Diseases. *Inflamm Bowel Dis*. 2018;**24**:1660-1669.
10. FIORINO G., ALLOCCA M., CHAPARRO M., COENEN S., FIDALGO C., YOUNGE L., GISBERT J.P. 'Quality of Care' Standards in Inflammatory Bowel Disease: A Systematic Review. *J Crohn's Colitis* 2019;**13**:127-137.
11. LOUIS E., DOTAN I., GHOSH S., MLYNARSKY L., REENAERS C., SCHREIBER S. Optimising the Inflammatory Bowel Disease Unit to Improve Quality of Care: Expert Recommendations. *J Crohn's Colitis* 2015;**9**:685-91.
12. FIERENS L., BOSSUYT P., BAERT F., BAERT D., LAVAERTS M., WELTENS C., FERRANTE M. Development of a core set of quality of care measurements for patients with inflammatory bowel disease in Belgium. *Journal of Crohn's and Colitis* 2023;**17**:i318-i319.