Development of EHR-extractable quality indicators for inflammatory bowel disease in general practice

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Abstract

Background: Inflammatory bowel disease is a major chronic disease and has seen its incidence rising over the last years. Because the diagnosis and treatment mostly occurs in hospital settings, general practitioners more often than not feel awkward about the management of IBD patients. The development of quality indicators (QI's) can be a helpful tool to assess, correct and optimize the quality of care in chronic diseases. If these quality measures are extractable from the Electronic Health Record, the process of quality assessment in primary care would become more automated and efficient. Our goal in this study is therefore to develop a set of evidence-based quality indicators, which are EHR-extractable, to enable automated quality assessment in general practice.

Methods: For this study, we used a RAND-modified Delphi method. Recommendations were selected out of international renowned guidelines and were included in a questionnaire based on the SMART-principle. This questionnaire was presented to a multidisciplinary expert panel, including patients, who individually scored these recommendations on a 9-point Likert scale. Based on the median score, the prioritization and agreement, recommendations were assigned as having a high, uncertain or low potential to measure quality of care. Next, a consensus meeting was held between the panel members to discuss the results. After final appraisal, the set of included recommendations were transformed into quality indicators.

Results: A list of 46 recommendations, obtained from 9 international guidelines, was presented to the panel. After the consensus meeting, a core set of 20 recommendations was translated into quality indicators. These QI's concern different subjects of IBD care such as diagnosis, prevention, pharmacological treatment, screening & monitoring and referral.

Conclusion: This study presented 20 EHR-extractable quality indicators for IBD care in general practice. These QI's can be used as a framework to automate quality assessment in primary care.

Introduction

Inflammatory bowel disease (IBD) is a major chronic condition with an increasing incidence worldwide [1-2]. The two most common subgroups are Crohn's disease (CD) and ulcerative colitis (UC) [1-3] Both pathologies have a strong impact on the quality of patient's lives, as the onset of the disease mostly occurs between the second and the fourth decade, and has features of both intestinal and extra-intestinal manifestations [3-5]. Inflammatory bowel disease is not curable. Treatment goals are to minimize symptoms, improve quality of life and minimize disease progression

and complications [1,5]. Given these characteristics, the general physician can play a major role in the early recognition and follow-up of IBD patients [6-8]. However, because the diagnosis is ideally confirmed by endoscopy and the treatment is mostly started in hospital setting [4,5], patients with IBD often consider their gastroenterologist to be the primary provider of care [7-8]. As a result, recent studies have shown that preventive health services are significantly lower in IBD patients than in primary care patients [7,9] and a large portion of general practitioners even feel uncomfortable managing IBD patients [8]. A recent systematic review highlighted the absence of education tools for IBD management in primary care setting [8]. Consequently, this can lead to more hospital admissions, suboptimal care and preventable health issues in IBD patients [7-9].

Above findings emphasize the importance of good co-management between general practitioners and gastroenterologists, as well as the need for supportive tools in the management of IBD in primary care. The development of a set quality indicators (QI's) has been proven a useful tool in the past to assess the quality of care and provide feedback to physicians' performances in the management of chronic diseases [10-12]. The Electronic Health Record has grown importance in these technological times and Campenella et al. have stated that proper implementation can lead to increased guideline adherence and quality of care [13]. As a result, if these quality indicators are subjected to coded data from the Electronical Health record (EHR), the quality assessment will be performed more efficient and automated [13-14]. This will allow general practitioners to internally review their quality of care by providing regular feedback reports, and compare them to the standard of excellence. Several renowned national and international guidelines have published QI's in relation to IBD-care over the years [15-17], but too few of them were applicable to non-specialist care [17,8]. The aim of our study is therefore to develop a set of reliable quality indicators, extractable from the EHR, to evaluate and improve the quality of care for IBD patients in the primary care setting.

Methods

Our study was performed between December 2022 and February 2024.

Study design

To attain quality indicators for IBD, the RAND-modified Delphi method was used [10-11,19]. The study was set up in five steps: (a) selection and transformation of recommendations and existing QI's from evidence-based guidelines into a written questionnaire round to present to an expert panel, (b) Individual scoring of the recommendations by the expert panel (c) a consensus round to determine the eligibility of each recommendation and to discuss the differences in assessment between the experts, (d) a final evaluation of the set of recommendations by the panellists, (e) Transformation of the recommendations into a final set of quality indicators.

Panel selection

To compile an adequate expert panel, multiple health care workers were contacted via e-mail, telephone or were asked for their cooperation in person. Three general practitioners, all with experience in the follow-up and treatment of IBD patients, were included. Two gastroenterologists with special knowledge in IBD agreed to cooperate and convinced their respective IBD-nurses to participate. Patients were recruited by their respective general practitioner. To meet inclusion

criteria, participating patients had at least been diagnosed with ulcerative colitis or Crohn's disease for 5 years. After being well informed with an information letter, all panel members subsequently signed an informed consent. The final expert panel consists of 3 GP's, 2 gastro-enterologists with special knowledge in IBD, 2 nurses with special knowledge in IBD, and 3 patients, previously diagnosed with IBD.

Selection of recommendations and Qis from evidence-based guidelines

In search for evidence-based recommendations and QI's, we consulted the MEDLINE database. The search terms: "inflammatory bowel disease" OR "IBD" OR "Crohn's disease" OR "Ulcerative colitis" AND "guideline" OR "quality indicator" OR "quality of care" OR "recommendations" were used. The search was also extended to the World Wide Web. Guidelines were selected both on the language (English and Dutch) and the year of publication (not older than 10 years). To ensure a high-quality list of guidelines, only guidelines developed by (inter)nationally renowned institutions were used.

Subsequently, an exhaustive list of all recommendations applicable to IBD was made. To determine which of these recommendations was fit for inclusion into a written questionnaire, the SMART principle [11,12,19] was used on each of the recommendations. SMART is an acronym for Specific, Measurable, Acceptable, Realistic and Timebound. For example, recommendations that were not specific or realistic in primary setting were excluded (e.g. Balloon-assisted enteroscopy or small-bowel capsule endoscopy may be useful for the close examination and follow-up of small bowel lesions in Crohn's disease). The SMART-principle was also used to assess the EHR-extractability. The remaining recommendations were then assembled into a questionnaire and assigned into 5 specific subdomains: diagnosis, prevention, pharmacological treatment, screening & monitoring and referral. This final list of recommendations was sent out to the panel, with an alternative questionnaire for patients as some recommendations were not eligible for non-healthcare workers.

Questionnaire round

Each panellist received the questionnaire by mail and was asked to rate the recommendations for their capability to measure the quality of care for IBD patients. This evaluation was made on a Likert scale from 1 to 9, with 1 being the lowest score (poor recommendation) and 9 being the highest score (good recommendation to measure the quality of care). In addition, the panel members were asked to confirm relevance or EHR-extractability for each recommendation. Panellist also had the option of labelling the recommendation as "not assessable", should they be unable to score the recommendation. After each subcategory, the panel members were asked to prioritize the recommendations with a top-5 rank along with its motivation. Finally, panel members were able to suggest new recommendations or write down remarks. The including patients in the expert panel received assistance from the author by going through each recommendation and to clarify where necessary.

Analysis

After receiving the questionnaires, all scores and remarks were entered into an Excel database and recommendations were classified into 3 different categories: having a high, uncertain or low potential to measure the quality of care in IBD patients. These categories were formed based on

three different criteria: the median Likert scale score, prioritization and degree of agreement along the panel members [11-12,20-21].

1) *Median Likert scale score*
   The median Likert scale score included the calculation of the median score given by all panel members for each recommendation or QI, ranging from 1 to 9. Non-assessable scores were not included into this calculation.

2) *Prioritization*
   Prioritization was a percentage, derived from the individual ranking of recommendations into the top-5 per subcategory. If a panel member ranked a recommendation first, it received 5 points, the second one 4 points, etc. A recommendation that was not included by a panel member into the top 5, received no points. Prioritization points were then added up and divided by the highest possible score for the recommendation. This fraction was ultimately converted into a percentage. For example, if 4 panel members ranked a recommendation first and 6 did not include it in their top 5, the prioritization would be 20/50 (5 x 10) or 40%.

3) *Agreement*
   Agreement was defined as ≥70% of the panel members awarding a score of ≥7. Discussion was determined as ≥30% of the panel members scoring ≥7 and ≥30% scoring ≤3. The other scores were defined as having no agreement.

Classification of recommendations
The Median Likert scale and the prioritization were determined as the preselection (Table 1). Together with the agreement, the recommendations were assigned into the three different categories, as shown in Table 2.

Table 1. Preselection

Preselection	**Median Likert score**	**Prioritization**
Selection	≥7	≥20%
Discussion	≥7	<20%
	<7	≥20%
No Selection	<7	<20%

Table 2. Classification of recommendations

Recommendation	Preselection	Agreement	Classification
Recommendation 1	Selection	Agreement	High potential
Recommendation 2	Selection	Discussion	Uncertain potential
Recommendation 3	Discussion	Agreement	Uncertain potential
Recommendation 4	No selection	Agreement	Uncertain potential
Recommendation 5	No selection	Discussion	Uncertain potential
Recommendation 6	Selection	No Agreement	Uncertain potential
Recommendation 7	Discussion	No Agreement	Uncertain potential
Recommendation 8	Discussion	Discussion	Uncertain potential
Recommendation 9	No selection	No Agreement	Low potential

Consensus round

After analysis, the results were presented to the panel members via a feedback report. This report contained all recommendations with their respective median Likert score, along with the percentage of prioritization and the agreement for each recommendation separately. In addition, the recommendations were highlighted with a colour: recommendations with high potential to measure quality of care were awarded a green colour, uncertain was highlighted with orange, and recommendations with low potential were coloured red. Additional recommendations and comments provided by the panel members were also included in the report. Next, an online consensus round took place to discuss the in- or exclusion of the recommendations based on the data of the feedback report. In this meeting, the recommendations with a high potential to measure quality of care (green colour) were briefly reviewed and included unless a panel member judged otherwise. Alike, the recommendations with low potential (red colour) were excluded unless deemed unjust by one of the panel members. Recommendations that were classified as uncertain (orange colour) were discussed more extensively until agreement for in- or exclusion was reached. Finally, all included recommendations were subjected to the SMART principle and remarks of the panellists to evaluate their EHR-extractability and their use in primary care setting.

Final appraisal

The set of recommendations obtained from the consensus meeting was sent to all panel members for a final appraisal.

Translation into QI

Ultimately, this final set of recommendations was transformed into QI's as a percentage. An example: the recommendation "Patients with IBD should be vaccinated annually against influenza" was translated to "Percentage of patients with IBD who are vaccinated against influenza annually".

Ethical approval

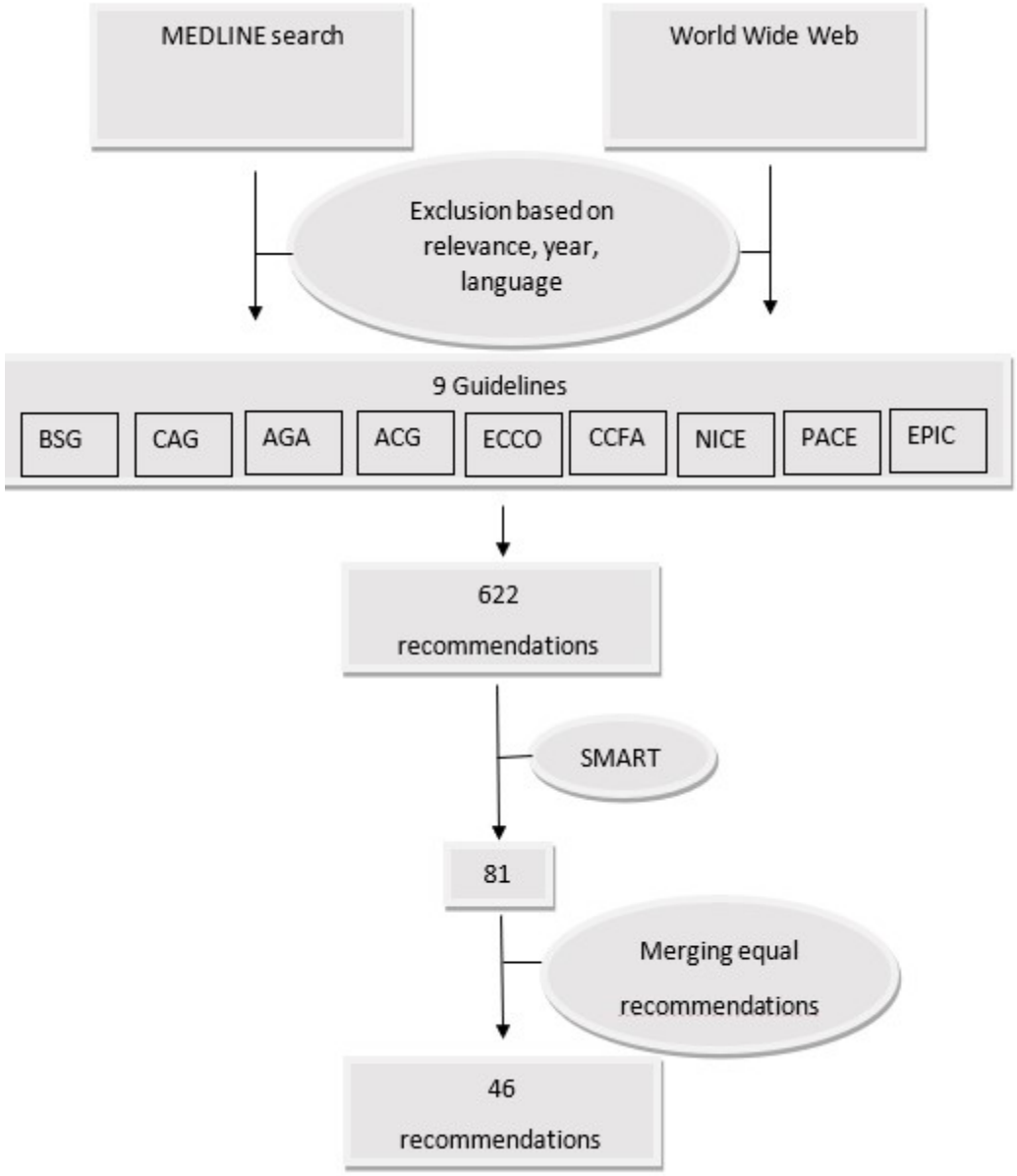
This study was ethical approved by the ethical committee of KU Leuven (SCONE) with reference number MP023590 on 07/03/23. All panel members submitted an informed consent upon participation.

Results

Selection of recommendations

Our search for evidence-based guidelines in MEDLINE and the World Wide Web yielded an exhaustive number of articles. Out of this list, 9 guidelines were selected based on their relevance, their publication date and their applicability to primary care [7,16,22-35]. A total of 622 Recommendations were obtained out of these guidelines (see addendum 1). Two authors (CV and MF) independently reviewed all recommendation statements for their eligibility and were in- or excluded in accordance with the SMART-principle. In case of disagreement, a third party (SVdB) was consulted. This resulted in 81 recommendations. Thereafter, the resulting recommendations were assigned into 5 different subcategories: diagnosis, prevention, pharmacological treatment, screening and monitoring, and referral. After merging similar recommendations, a total of 46 recommendations formed the written questionnaire (see table 3)

Table 3. Selection of recommendations



Questionnaire round

These 46 statements were sent out to the panel members for individual rating (see addendum 2). For patients, only 17 recommendations were presented (see addendum 3), as some subjects were not possible to fill in as non-professionals (e.g. Pharmacological treatment). The questionnaire had a response rate of 100%. After analysis based on the median Likert scale, prioritization and agreement 23 recommendations were marked green, defined as having a high potential to measure quality of care, 8 red-coloured recommendations with a low potential and 15 recommendations who needed further discussion.

Consensus meeting round

Two gastro-enterologists, three general practitioners and one IBD nurse participated in an online consensus meeting to discuss above findings. While reviewing the pre-panel selected recommendations, it became clear that initial high quality recommendations concerning pharmacological treatment were not supported by primary care providers and were subsequently, after agreement by all attendees, excluded. This resulted in inclusion of 19 of the initial 23 green recommendations. None of the preliminary excluded recommendations were selected. After a round of discussion, 4 of the uncertain recommendations were considered for selection. Next, the resulting 23 recommendations were once more subjected to the SMART-principle and assessed for their EMR-extractability, which resulted in a final set of 20 recommendations.

Final appraisal

After the consensus meeting, the final list was provided by email to all panel members for final appraisal. Two of the initial ten panel members did approve tacitly to this final list. The other eight communicated not to have any remarks and agreed explicitly to the final list of recommendations.

Transformation of recommendations into QI's

All 20 recommendations were translated into QI's. The resulting list contains 3 QI's regarding diagnosis, 6 QI's regarding prevention, 2 QI regarding pharmacological treatment, 6 QI's regarding screening and monitoring and 3 QI's regarding referral.

Final list of QI's

Table 4: Final set of QI

Diagnosis

1. Percentage of patients between 16 and 40 years old with chronic diarrhoea or symptoms that may be consistent with IBS or IBD, who are tested with fecal calprotectine.*

   *Symptoms include: (recurrent) abdominal pain, diarrhea, bloody stools, urgency or fecal incontinence, rectal bleeding, weight loss, fever, malnutrition and delayed growth in people who develop IBD as children

2. Percentage of patients with elevated fecal calprotectine (>50 µg), who are referred within 4 weeks to a gastro-enterologist

3. Percentage of patients with possible IBD, who have undergone a stool testing to rule out Clostridium difficile

Prevention

4. Percentage of patients with IBD, who have been encouraged to quit smoking despite having an increased risk of flare after stopping in ulcerative colitis

5. Percentage of patients with IBD who received an annual influenza vaccination.

6. Percentage of patients with IBD, who are older than 50 years, who received a pneumococcal vaccination every 5 years.

7. Percentage of patients with IBD who receive immunosuppressive therapy, in whom live vaccines are avoided/are not prescribed because they are considered unsafe.

8. Percentage of patients with IBD in whom NSAIDS are avoided/is not prescribed because of risk of exacerbation

9. Percentage of patients with IBD who are vaccinated for hepatitis B until anti-HBs antibodies are above 10 IU/L

Pharmacological treatment

10. Percentage of patients with IBD who received two or more treatments of oral corticoids in one year. These patients should be considered to be treated with a steroid sparing agent

11. Percentage of patients with IBD who received oral corticoids >10mg a day for more than 16 weeks. These patients should be considered to be treated with a steroid sparing agent

Screening and monitoring

12. Percentage of patients with IBD, who commence with immunomodulators or biologicals, who are screened for HBV, HCV, VZV and HIV

13. Percentage of patients with IBD, who are treated with thiopurine or methotrexate, in whom blood tests including FBC, U&E and LFT are carried out 3-monthly.

14. Percentage of patients with IBD who are routinely asked about medication adherence. Non-adherence is common and results in worse outcomes. Risk factors include young age,

psychological distress, patient beliefs and discordance between patient and health professional.

15. Percentage of patients with IBD, who are screened at least once a year for malnutrition by measuring length and weight, and if necessary assessment for macro- or micro- deficiencies in blood sample.

16. Percentage of patients with IBD who are asked regularly about stress, anxiety and depression.

17. Percentage of patients with IBD who have undergone ileocolonoscopy 8 years after symptom onset to screen for neoplasia

Referral

18. Percentage of patients with IBD, who are admitted to hospital when acute severe colitis is suspected. This includes >6 bloody stools per day and systemic toxicity with at least one of: temperature >37.8°C, pulse >90 bpm, haemoglobin <105 g/L or C-reactive protein >30 mg/L.

19. Percentage of patients with IBD, with acute eye pain or visual changes, who are referred to an ophthalmologist

20. Percentage of patients with IBD who are referred to a rheumatologist in case of IBD-related arthropathy

Discussion

This study, applying the RAND/Delphi method, resulted in the making of 20 quality indicators which are evidence-based and EHR-extractable. This set of quality indicators covers different aspects of IBD-care such as diagnosis, prevention, pharmacological treatment, screening and monitoring, and referral. Since the goal of the study was to make these quality indicators EHR-extractable, they could be implemented to draw up automated feedback reports or internal audits. This will allow general physicians to assess and improve various features of primary care in IBD patients.

Selection and approval of the quality indicators was made by a multidisciplinary expert panel, consisting of different but equally important shackles in the care of IBD patients. GP's, gastro-enterologists, IBD-nurses and also patients were included to maximize heterogeneity. We decided not to include gastrointestinal surgeons, as referral to surgery is almost explicably made by gastro-enterologists [36] and recommendations found in international guidelines were excluded based on

the SMART-principle. However, it is important to state that surgery is a cornerstone in the treatment of IBD-patients, as approximately 20% of ulcerative colitis patients and even 60% of patients with Crohn's disease will require surgery in their lifetime [36-38]. Although the decision-making and follow-up will mostly be provided in hospital settings, general physicians should be aware of common postoperative complications such as stoma issues, anastomosis leaks, malnutrition and micro- or macro deficiencies [39,40].

The initial list of recommendations, as presented to the panel, included 16 recommendations concerning pharmacological treatment of IBD, from initiating treatment to keeping the disease in remission with maintenance therapy. After the questionnaire round, 6 of these recommendations were included for selection, 7 recommendations required further discussion and 3 recommendations were considered not suited for selection. However, if we took a closer look at these results, we noticed that most of these recommendations were scored as "not assessable" by general practitioners and IBD nurses, as they did not have the knowledge or were uncomfortable to grade these recommendations. Given the fact that patients received a questionnaire without the topic of pharmacological treatment, most of these recommendations were only answered by gastro-enterologists. We shared this findings during the consensus round, which opened up an interesting debate about what the responsibility of primary care should be in the treatment of IBD patients. All GP's were present at the consensus meeting and expressed their difficulties in treating IBD patients. This is mainly due to the medication being highly specific, in combination with a low prevalence of IBD patients in their patient population. Other obstacles highlighted were the fact that remission should often be evaluated endoscopically, and more advanced therapeutic strategies (e.g. immunosuppressive therapy, thiopurines) are not reimbursed in Belgium unless prescribed by gastro-enterologists. As a result of this discussion, most of the recommendations regarding treatment were removed from the final list of recommendations. The overall consensus pleaded that if a general practitioner suspects a first presentation or disease flare, the most import action to do is to refer to a gastro-enterologist for further assessment and potential treatment. However, if he does feel confident regarding different treatment options, or he is well informed about the treatment in previous disease flares, he has the option of already commencing therapy before referral.

Nevertheless, the panel was unanimous that the general practitioner can play a key role in the protection of corticosteroids-overuse in the treatment of IBD patients. Although effective for induction of remission [2,41], the prolonged use of corticosteroids is associated with multiple side effects such as osteoporosis, diabetes, and even increased mortality [41-43]. Despite the rising development of multiple steroid-sparing strategies [1-2,42], Dorrington et al. noticed no difference in the prescribing of corticoids in European IBD patients over significant periods of time [43]. A study by Ghosh et al. highlighted that health care workers significantly underestimate patients' corticoid use in Crohn's disease [44]. By developing a quality indicator to measure the use of corticoids in IBD patients, physicians will be able to monitor the usage of corticosteroids and intervene when necessary.

Multiple studies suggest that good co-management between general physicians and gastroenterologists is indispensable in the complex model of care for IBD patients [7-9]. Whereas the main focus of gastroenterologists lies with treatment and maintenance of remission in IBD patients, the primary care provider can play a big part in the prevention, detection and monitoring of complications [7-8, 45]. Hence, it is no surprise that the resulting quality indicators, intended to use in

primary care, are mostly fixated on these subjects. For example, patients with IBD, especially those on immunomodulators and biologic agents, are at increased risk of infections, many of which preventable with vaccines [1-3,46]. As a result, recommendations regarding the vaccination of influenza, pneumococcal and hepatitis B were selected by the panel. Meningococcal vaccination or HPV vaccination were withheld by the panel, as they were deemed not specific enough for IBD care. Furthermore, since IBD onset frequently occurs at a young age, the diagnosis often carries a heavy physical and mental burden with it. Absence in school or work, stress, anxiety, depression and suboptimal medication adherence are all more common in IBD patients [9,34,47]. The panel stressed the importance of these problems and believe more awareness should be created to recognize and address these complications sooner rather than later.
IBD is characterised not only with intestinal complications, but also with extra-intestinal manifestations [5,31] and an increased risk of malignancy [29,48]. Extra-intestinal manifestations include musculoskeletal, cutaneous and ocular manifestations. Studies have shown an increased risk of colorectal cancer, cervical dysplasia and skin cancer. Some of these potential consequences were integrated in our set of QI's (e.g. patients with visual changes are referred to an ophthalmologist), others were not selected as they were judged to be not feasible (e.g. annual cervical screening), or were not selected in the first place based on the SMART-principle (e.g. IBD patients should be screened for skin conditions) or their EHR-extractability (e.g. sun protection in IBD patients).

There have been published QI's on IBD in the past [15-17, 33-35], but many of them were only applicable in hospital settings or were not EHR-extractable. A recent study by Fierens et al. also defined a set of quality measures using the Delphi method, destined for Belgian IBD centres [49-50]. This set of quality measures naturally contained some similarities with our list (e.g. 5-yearly pneumococcal vaccination, smoking status and measuring of body weight, …), but were largely fixated on the organization and functionality of multidisciplinary teams in hospital settings.
It is our belief that by applying the SMART-principle, as well as taking account the possibility to extract coded data from the EHR, we create an independent framework to analyse primary care for IBD. This may lead to automated quality control and subsequent optimalisation of care in IBD patients.
Another strength of this study is that the developed QI's are based on 9 (inter)national guidelines, which makes it possible to use this set across different countries. This would require further testing, beginning with a clinical practice test of this set in Belgian electronic health records. By using a multidisciplinary expert panel, it was possible to cover various aspects of IBD-care. The inclusion of patients provided beneficial insights in the healthcare needs and concerns of IBD patients.

However, there are several limitations to our study. As previously mentioned, surgeons were excluded from the multidisciplinary panel. The majority of panel members did not have any experience with the RAND/Delphi method and the development of QI, let alone the extractability of QI's from the EHR. This could have led to over- or underrating recommendations, with in- or exclusion of invalid recommendations as consequence. Panel members often rated recommendations as "non-assessable" because of knowledge gaps in managing of IBD, or lack of encounter with IBD-patients,. This caused recommendations to be rated solely by one or two disciplines, with their judgement carrying more weight. The three patients that filled in the questionnaire were not present in the consensus meeting and could not clarify their choices and mix in the discussions. They did however had the chance to make remarks after the list was sent out to all panel members for final appraisal.

Conclusion

This study resulted in a set of 20 evidence-based quality indicators to measure the quality of primary care for inflammatory bowel disease. Because of their extractability from the electronic health record, it is possible for the general practitioner to generate an automated feedback report to assess and improve quality of care.

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