Development of a Global Rating Scale for Inflammatory Bowel Disease

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ABSTRACT

Background: The Global Rating Scale (GRS) is a web-based self-assessment quality improvement tool used to identify gaps in health care, change the focus to patient-centred care and standardize care. There are four levels of achievement ranging from basic-(D) to excellent-(A) service delivery. The goal was to develop a GRS for inflammatory bowel disease (IBD) to improve the quality of care for patients on a system level.

Methods: The IBD GRS was developed through an iterative process and modeled upon the successful endoscopy GRS programs in the United Kingdom and Canada. Dimensions, items and statements were drafted based on expert opinions, patient-informed quality indicators and best available evidence, then reviewed and modified by a core committee. A working group of IBD and GRS experts voted in-person to establish consensus on the inclusion and quality of statements.

Results: Two dimensions (Clinical Quality and Quality of Patient Experience), 10 items and 89 statements made up the IBD GRS. There was a 100% response rate for each of the 40 votes for statements in the IBD GRS. All statements within each level received a mean rating score between four (agree) and five (strongly agree). Revisions agreed upon during the voting process were incorporated into the IBD GRS. Group consensus was achieved on the inclusion of statements, and 10 items were selected as standards within the two dimensions.

Conclusions: We have developed the first IBD GRS with the aim of improving quality of care through ongoing evaluations and improvements by health care teams, focusing on patient-centred care.

Keywords: Ulcerative colitis; Crohn's disease; Global rating scale; Inflammatory bowel disease; Quality improvement
INFLAMMATORY BOWEL DISEASE

Inflammatory bowel disease (IBD) describes a group of chronic inflammatory intestinal conditions, the two main forms of which are Crohn’s disease and ulcerative colitis. IBD is associated with both environmental and genetic risk factors (1). North America and Europe have, traditionally, some of the highest IBD incidence rates in the world (2–5). In Europe, as of 2013, an estimated 0.3% of the population (2.5 to 3 million) suffer from IBD, with approximately 256,000 new cases each year and direct health care costs estimated between €4.6 and 5.6 billion annually (3,6–8). Approximately 3 million adults in the United States have been diagnosed with IBD, accounting for an estimated 1.89 million out-patient visits and 1% of emergency department visits annually (9–13). In 2015, the National Health Interview Survey conducted in the United States indicated the prevalence of IBD among adults has increased and far exceeds previous estimates (9). In 2018, approximately 270,000 Canadians were living with IBD with an estimated 10,200 incident cases occurring every year (14–16). Current estimates by researchers suggest that by 2030 the number of Canadians living with IBD will reach approximately 388,000, 0.95% of the population (15). Recent studies suggest an increasing prevalence of IBD in North American and European populations (2,3,15,17–20). Additionally, the incidence of paediatric onset IBD and IBD in second-generation immigrants is increasing (14,21,22). IBD is a disabling, chronic lifelong disease with afflicted individuals requiring ongoing care. The increasing prevalence of the disease will result in a larger burden on health care systems for European and North American populations (14,23,24).

Variability in care delivery is associated with variation in quality of care. Thus, variable health care access and delivery for IBD patients create significant gaps and barriers to improving quality of care. Current practice patterns vary among IBD health care providers, in North America and Europe, for key therapeutic decisions in the management of Crohn’s disease and ulcerative colitis (25–28). Strategies to mitigate these barriers require the development and implementation of innovative models to enhance care delivery nationally in a standardized and monitored setting (23–25,29).

GLOBAL RATING SCALE

The Global Rating Scale (GRS) is a web-based self-assessment tool with which health care providers may periodically review the quality of care delivery, as well as the impact of enhancements to care services (30). The GRS can be used to identify gaps in care, change the focus to patient-centred care and standardize care on a national level. It is an innovative model designed to establish standardized, and where possible evidence-based, milestones and self-assessment metrics for ongoing quality improvement activities for IBD clinics and health care professionals. The GRS is completed annually or bi-annually to determine the level for quality of service delivery. Based on defined metrics, strategies can be developed to elevate the clinic or health care professional to the next level. It requires an ongoing evolution of evaluation and improvement strategies in order to reach better levels of service delivery.

The GRS was developed in 2005 in the United Kingdom to assess patient-centred care in endoscopy. The development of the UK GRS was prompted by the introduction of the colorectal cancer screening program and gaps identified in the quality of care in endoscopy. It is currently used to support accreditation by the Joint Advisory Group on Gastrointestinal Endoscopy and has led to substantial improvements in quality of care and wait times for UK endoscopy patients (31–33). In a study assessing the applicability of the UK GRS, it was determined to be an appropriate tool for use by health care providers and organizations outside of England (34). In 2007, the Canadian Association of Gastroenterology (CAG) adapted the UK GRS to the Canadian health care infrastructure, language and current practices for Canadian endoscopy patients as a pilot project at 12 sites (35,36). As of 2018, over 190 sites and over 500 participants nationwide use the Canadian endoscopy GRS (C-GRS) (37). In 2016, the validity and reliability of the C-GRS for endoscopy services was tested at three centres in Canada. The participating centres reported satisfactory face validity, content validity, construct validity and reliability (36). In 2018, CAG will launch an enhanced GRS platform that will accommodate multiple GRS, including IBD.

The GRS has three different layers: dimensions, items and statements. There are four levels of achievement that range from basic service delivery (level D) to excellent service delivery (level A) (Table 1). Level D involves basic measurements, level C periodically reviews basic measurements, level B will act upon information received from the review of basic measurements and level A monitors the effectiveness of the actions that were taken based upon the review of basic measurements.

| Level | Activity | Achievements |
|-------|----------|--------------|
| A     | Observations are recorded, reviewed, and acted upon and monitored for effectiveness | Excellent service |
| B     | Observations are recorded, reviewed and acted upon |                |
| C     | Observations are recorded and periodically reviewed |                |
| D     | Observations are recorded | Basic service |

Data taken from ref. (35).
at level A are considered best practice standards based upon current, evidence-based or expert recommendations (30,35). By identifying metrics, the GRS has the potential to raise standards of care and to foster a teamwork environment. It provides each participating institution with a process to continuously review quality of care, and a framework to measure the improvements in service delivery by increasing their status on the GRS.

IBD GRS was created as a novel initiative in collaboration with Crohn's and Colitis Canada and CAG to evaluate and enhance the quality of IBD care across Canada. The IBD GRS was also informed by the IBD quality indicators that were developed to measure benchmarks in IBD health care delivery. The development of the IBD quality indicators included patient focus groups and a consensus process involving patient partners (38). The IBD GRS will benefit IBD centres, clinics and offices in academic and community settings. It also has the potential to be exported to other countries, just as the C-GRS was adapted from the UK GRS. Further, it will serve as a complimentary tool for Crohn's and Colitis Canada's quality initiative Promoting Access and Care through Centres of Excellence (PACE) (39).

The objective of this project was to develop the first GRS for IBD in order to standardize care on a system level and support quality improvement activities by identifying gaps in care.

**MATERIALS AND METHODS**

Institutional ethics board approval was not required for this study since it did not involve human subjects as research participants.

In 2016, an eight-person core committee was formed comprising of two nonmedical representatives from Crohn's and Colitis Canada, five physicians with expertise in IBD and development of clinical practice guidelines (A.B., V.J., A.W., P.M. and G.N.), and one physician with expertise in the endoscopy C-GRS (C.D.). The C-GRS was used as a template to establish the dimensions, items and statements to be considered for the IBD GRS (30,35,40). Content from the IBD quality indicators, including patient-informed statements, was also used as a framework for the IBD GRS content. Patient focus groups, held across Canada, identified and helped develop patient-informed IBD quality indicators (38). The IBD quality indicators helped inform the content of the IBD GRS that was developed by the core committee which included physicians (38). A preliminary IBD GRS with 2 dimensions, 12 items and 114 statements was developed, based on expert opinions and best available evidence, for dissemination at a face-to-face meeting in November 2016. One representative from CAG (P.M.) joined the core committee to participate in the review of the dimensions and items. The feasibility of each item, the applicability to IBD service delivery and the distribution of tasks to modify the 114 statements was discussed amongst the core committee members (Figure 1).

Following the November 2016 meeting, three members of the core committee (V.J., A.W. and G.N.) were each tasked with reviewing and editing four items. Following these revisions, all 12 items were independently reviewed and edited by two reviewers (C.D. and P.M.). Based on the feedback, a second draft of the IBD GRS was prepared by one member of the core committee (A.B.). In March 2017, this version, reduced to two dimensions, 10 items and 89 statements, was reviewed during a face-to-face meeting of eight IBD experts (one nurse practitioner, seven clinicians) (J.H., B.B., P.M., V.J., J.J., G.N., A.W. and A.B.) and two C-GRS experts (C.D. and D.M.). Participants voted to establish consensus on the inclusion of statements and the quality of the statements. Participants scored the statements, within their specified levels, anonymously using a five-point Likert scale ranging from strongly disagree to strongly agree. The scores were not applied to each statement independently but to the one or more statements included in each level ranging

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**Figure 1.** Methodology for achieving expert consensus on an inflammatory bowel disease global rating scale (IBD GRS) tool.
from A to D. GRS is a process for improving care with timelines and re-evaluation; the statements guide users to evolve up the levels. Statements in level D reflect the basic level of service delivery, consisting of documentation of observations only. Statements in level A reflect excellent care delivery with areas for improvement identified, acted upon and monitored for effective changes (Table 1).

Data Collection and Analysis
The anonymous voting results were collected and entered into an Excel database. Each participant had the opportunity to vote on the statements within each level for all 10 items, a total of 40 votes were required per participant. The vote was in the form of a score for all the statements included in the level, not for each statement. The results were tabulated and the mean score was reported.

RESULTS
Two dimensions, Clinical Quality and Quality of Patient Experience, were selected to categorize the statements for aspects of IBD care delivery (Figure 2). There was a 100% response rate for each of the 40 votes for the 10 IBD GRS items. The mean rating scores and the final version of the IBD GRS are reported in Tables 2 and Tables 3. All statements, grouped by level, received a mean rating score between four (agree) and five (strongly agree). Revisions agreed upon during the voting process were incorporated into the IBD GRS. Group consensus was achieved on the inclusion of all statements, and the following 10 items were selected as standards within each dimension.

Dimension: Clinical Quality

Patient Information Sheet
To obtain level D, facilities should publish a patient information sheet in written and/or electronic form. Patients should also be provided with contact information for relevant resources and the risks and benefits of steroids, immunosuppressants or biologic therapy. To advance to a level C facility, patient satisfaction surveys (41) should be performed and patient information should be reviewed and updated annually. Advanced care delivery (level B) requires an IBD clinic to respond to perceived deficiencies by making changes within 6 months of receiving feedback regarding patient information sheets. To improve to level A, the IBD clinic must review the impact of the changes made to the information sheets using an annual survey and health care provider review.

Patient Safety
IBD clinics should have a system for recording IBD management-related adverse events (42). Key safety indicators and auditable outcomes should be recorded by the clinic in paper and/or electronic form. The IBD clinic should also have standardized safety or monitoring protocols when initiating and continuing immunosuppressive and biologic therapy (level D). Quality of care delivery is increased to level C when an IBD clinic reviews adherence with standardized safety monitoring protocols; has a responsible committee or individual to annually review IBD management-related adverse events; and IBD clinic practitioners or nurses are provided with reports on the adverse event rates for their patients at least once a year. Level B requires actions to be implemented within 6 months of a review to improve adherence to safety monitoring protocols, and in response to safety indicators and auditable outcomes. A level A facility must have a responsible committee or individual to review the impact of actions taken.

Dimension: Quality of patient experience

Patient Well-Being
A process should be in place in all IBD clinics for the assessment of a patient’s general well-being and disease-related

![Diagram](Figure 2. Dimensions and items in the inflammatory bowel disease global rating scale (IBD GRS).
### Table 2. Aspects of inflammatory bowel disease (IBD) care delivery associated with the dimension of clinical quality

| Item | Statement | Level | Mean rating score, (1–5)* |
|------|-----------|-------|----------------------------|
| Patient information sheet | 1.1 There is a published patient information sheet, available in written and/or electronic form, describing the: Diagnosis Investigations including blood work, imaging and endoscopy Drug therapies Nutritional support Possible surgical interventions | D | 4.6 |
| | 1.2 Patients are provided with contact information for regional or national patient advocacy groups, patient support programs or other IBD resources | D | |
| | 1.3 Information sheets outlining risks and benefits are provided to patients prior to initiating steroids, immunosuppressives or biologic therapy | D | |
| | 1.4 Patient satisfaction surveys, which include questions regarding quality of the information, are performed at least once per year | C | 4.1 |
| | 1.5 The IBD clinic annually reviews patient information materials to ensure they are up to date | C | |
| | 1.6 The IBD clinic makes changes within 6 months to patient information sheets suggested by patient survey and health care provider review | B | 4.0 |
| | 1.7 The IBD clinic reviews the impact of changes made to information sheets in an annual survey and health care provider review | A | 4.1 |
| Patient safety | 2.1 The IBD clinic has a system for recording IBD management-related adverse events including: Drug Endoscopy Radiology Surgically related interventions | D | 4.4 |
| | 2.2 Key safety indicators and outcomes are recorded by the clinic in paper and/or electronic form, and are auditable | D | |
| | 2.3 The IBD clinic has standardized safety/monitoring protocols when initiating and continuing immunosuppressive and biologic therapy | D | |
| | 2.4 Compliance with standardized safety monitoring protocols are reviewed annually | C | 4.4 |
| | 2.5 A responsible committee or individual reviews IBD management-related adverse events at least once a year | C | |
| | 2.6 Clinic practitioners/IBD nurses are provided with reports on the adverse event rates for their patients at least once a year | C | |
| | 2.7 Actions to improve adherence to safety monitoring protocols are implemented within 6 months of review | B | 4.2 |
| | 2.8 Actions on safety indicators and auditable outcomes are implemented within 6 months of review | B | |
| | 2.9 A responsible committee or individual reviews the impact of actions taken to improve adherence to safety monitoring protocols | A | 4.2 |
| | 2.10 A responsible committee or individual reviews the impact of actions taken in response to adverse events | A | |
| Item | Statement | Level | Mean rating score, (1–5)* |
|------|-----------|-------|--------------------------|
| Patient well-being | 3.1 There is an assessment of the patient’s general well-being and disease-related psychological distress | D | 4.6 |
| | 3.2 There is an assessment of the patient’s days missed from work, school or routine responsibilities due to IBD | D | |
| | 3.3 The patient is provided with education on the common adverse consequences of IBD on general well-being and mental health | D | |
| | 3.4 There is a formal assessment of patient’s general well-being and disease-related psychological distress at each clinic visit | C | 4.1 |
| | 3.5 Documented impairment or interval decrease in quality of life or well-being prompts a review of the patient’s treatment plan | C | |
| | 3.6 Patient surveys assessing the clinic’s acknowledgement and management of patients’ general well-being and disease-related psychological distress are performed at least once a year | C | |
| | 3.7 Anonymized data on patient well-being assessment is fed back to individual IBD clinicians and the IBD clinic at least once a year | B | 4.0 |
| | 3.8 Action is taken to address patient satisfaction of the clinic’s management of general well-being and disease-related psychological distress at least once a year | B | |
| | 3.9 Impact of action taken to manage patients’ general well-being and disease-related psychological distress is reviewed within 1 year to ensure issues have been dealt with | A | 4.2 |
| Quality of disease management | 4.1 The facility has a paper or electronic system for recording IBD care-related quality indicators and auditable outcomes | D | 4.6 |
| | 4.2 The IBD clinic has a list of quality indicators that are agreed upon as an acceptable standard of care, as defined by the IBD clinic | D | |
| | 4.3 The IBD clinic uses an electronic health record to record and analyze IBD care-related quality indicators | C | 4.5 |
| | 4.4 There exists a mechanism to review the quality indicators and auditable outcomes once a year | C | |
| | 4.5 IBD clinicians/health care providers receive feedback on their individual quality indicator outcomes at least once a year | C | |
| | 4.6 A plan of action, including goals & timeline, is adopted with individual IBD clinicians if their performance does not meet acceptable standards | B | 4.0 |
| | 4.7 There is a mechanism to review and make recommendations to IBD clinics or IBD clinicians who do not meet performance standards and benchmarks after an agreed upon timeline | B | |
| | 4.8 The IBD clinic reviews the impact of recommendations made to achieve performance standards within 1 year | A | 4.4 |
| Appropriateness of treatment and investigation | 5.1 Guidelines for the use of specific therapies, investigations and for follow-up intervals are available in paper and/or electronic form | D | 4.6 |
| | 5.2 Guidelines for surveillance colonoscopy for dysplasia are available | D | |
| | 5.3 There are agreed upon standardized protocols for monitoring disease activity | D | |
Table 2. Continued

| Item   | Statement                                                                 | Level | Mean rating score, (1–5)* |
|--------|---------------------------------------------------------------------------|-------|---------------------------|
| 5.4    | There are agreed upon standardized protocols to monitor disease-           | D     |                           |
|        | associated adverse events such as bone health, nutritional status, etc.   |       |                           |
| 5.5    | The IBD clinic has a defined protocol for transition of care from         | D     |                           |
|        | paediatric to adult                                                      |       |                           |
| 5.6    | The IBD clinic has a protocol for managing special and vulnerable IBD     | D     |                           |
|        | populations                                                              |       |                           |
| 5.7    | There is a mechanism to assess the proportion of patients undergoing      | C     | 4.4                       |
|        | surveillance colonoscopy, according to established guidelines             |       |                           |
| 5.8    | The IBD clinic performs annual audits of adherence to guidelines and      | C     |                           |
|        | standardized protocols for the use of specific treatments and             |       |                           |
|        | investigations                                                            |       |                           |
| 5.9    | IBD clinicians receive the results of the annual appropriateness audits  | C     |                           |
| 5.10   | There is a mechanism that provides an action plan within 6 months of     | B     | 4.3                       |
|        | audit results if suboptimal performance is identified on the annual audit|       |                           |
| 5.11   | The facility reviews the impact of changes made to therapy and           | A     | 4.3                       |
|        | investigation practices, within 1 year                                    |       |                           |

| Communicating management plans and results | Item | Statement                                                                 | Level | Mean rating score, (1–5)* |
|-------------------------------------------|------|---------------------------------------------------------------------------|-------|---------------------------|
| 6.1                                       | IBD  | IBD clinic letters are dictated/written and sent to the referring         | D     | 4.6                       |
|                                            | clinic| physicians within 10 working days of the patient’s clinic visit          |       |                           |
| 6.2                                       |      | A summary of pertinent changes to therapy, planned investigations          | D     |                           |
|                                            |      | and follow-up is available in the patient’s chart when the patient      |       |                           |
|                                            |      | leaves the clinic                                                        |       |                           |
| 6.3                                       |      | Copies of relevant investigation reports are sent to the IBD clinic       | D     |                           |
|                                            |      | practitoner and to the referring physician, with clear                    |       |                           |
|                                            |      | communication as to who should act on the results                        |       |                           |
| 6.4                                       |      | The IBD clinic practitioner is responsible for ensuring that test         | D     |                           |
|                                            |      | results are conveyed to the patient                                      |       |                           |
| 6.5                                       |      | There are standard reporting elements for communicating results to       | C     | 4.3                       |
|                                            |      | patients and the referring physicians                                   |       |                           |
| 6.6                                       |      | Survey of patients assessing the quality of how results and management    | C     |                           |
|                                            |      | plan are communicated are performed once a year                          |       |                           |
| 6.7                                       |      | Annual audits of IBD clinicians’ adherence to standardized completion of  | C     |                           |
|                                            |      | clinic letters detailing key findings and key elements of the management  |       |                           |
|                                            |      | plan are performed                                                        |       |                           |
| 6.8                                       |      | Action is taken if patient and/or physician assessments of the           | B     | 4.2                       |
|                                            |      | quality of communication fall below agreed upon levels, as defined by    |       |                           |
|                                            |      | the IBD clinic.                                                          |       |                           |
| 6.9                                       |      | Audits of referring physicians assessing the quality of how results and  | B     |                           |
|                                            |      | management plan are communicated are performed once a year               |       |                           |
| 6.10                                      |      | The clinic implements an action plan within 6 months if problems          | B     |                           |
|                                            |      | are identified in the audit of clinic letters and/or test result          |       |                           |
|                                            |      | notification procedures                                                  |       |                           |
| 6.11                                      |      | The impact of action plans implemented in response to the audits of      | A     | 4.4                       |
|                                            |      | IBD clinicians’ adherence to communication metrics are reviewed           |       |                           |
|                                            |      | within 1 year                                                            |       |                           |

*Based on a five-point Likert scale (1 = strongly disagree, 5 = strongly agree).
### Table 3: Aspects of inflammatory bowel disease (IBD) care delivery associated with the dimension of quality of patient experience

**Dimension: Quality of Patient Experience**

| Item | Statement | Level | Mean rating score, (1–5)* |
|------|-----------|-------|--------------------------|
| **Access** | 7.1 The clinic provides a contact number and/or e-mail address (e.g., IBD nurse contact information), when the patient leaves the clinic, to answer questions regarding the findings, treatment, tests and follow-up appointments | D | 4.8 |
| | 7.2 All patients receive specific information, in written or electronic form, of all procedures to be scheduled before they leave the clinic | D |
| | 7.3 The IBD clinic provides patients with a mechanism (e.g., access to an IBD nurse) for accessing urgent appointment or other care during periods of disease flare | D |
| | 7.4 The clinic has a mechanism to triage and return phone calls based on urgency and type of request | D |
| | 7.5 Patient surveys to assess satisfaction with response to patient initiated communication are performed once a year | C | 4.3 |
| | 7.6 Patients surveys regarding the access to the clinic and to information are performed at least once a year | C |
| | 7.7 Actions on benchmarks for access to clinic and information are undertaken in response to patient surveys within 6 months | B | 4.2 |
| | 7.8 The clinic reviews the impact of changes made to access to the clinic and to information within 1 year of the response to the survey | A | 4.3 |
| **Booking and clinic visit** | 8.1 There is confirmation that patients are informed of their appointment | D | 4.6 |
| | 8.2 The IBD clinic provides sufficient and readily accessible patient toilet facilities | D |
| | 8.3 Scheduled time and actual start time of clinic visits are recorded | D |
| | 8.4 No-show and cancellation rates are monitored; relevant factors are noted (patient-related, referring MD, distance, weather) | D |
| | 8.5 Referring physicians and family physicians are notified if patients miss appointments (along with guidance regarding rescheduling) | C | 4.6 |
| | 8.6 Patients receive a reminder prior to their appointment | C |
| | 8.7 The clinic records the proportion of patients who are delayed in clinic | C |
| | 8.8 Feedback on booking process and clinic visit is elicited by an annual patient satisfaction survey | C |
| | 8.9 The clinic responds to feedback with action plans within 6 months of the response to the survey | B | 4.4 |
| | 8.10 The IBD clinic makes changes if the no-show or cancellation rates exceed agreed upon acceptable rates, as defined by the IBD clinic | B |
| | 8.11 The clinic reviews the impact of changes made to improve issues with booking and clinic visits and corrects problems within 1 year | A | 4.4 |
| **Timeliness of care** | 9.1 The IBD clinic has formal criteria to prioritize new referrals as: urgent, semiurgent, routine or second opinion | D | 4.6 |
| | 9.2 The IBD clinic documents wait times for consultations by priority level (urgent, semiurgent, routine or second opinion) | D |
| | 9.3 The IBD clinic documents wait times for consultations to multidisciplinary specialty services: Colorectal surgery Dermatology Rheumatology Psychiatry/Psychology | D |
psychological distress (43–45). Additionally, there should be an assessment for the number of days a patient has missed work, school or routine responsibilities due to their IBD. The patient should be provided with education on common adverse consequences of IBD on general well-being and mental health. Level C IBD clinics must have a formal assessment of general well-being and disease-related psychological distress at each clinic visit. Documentation of impairment or interval decrease in quality of life or well-being should prompt a review of the treatment plan. Further, patient surveys assessing clinic’s acknowledgement and management of general well-being and disease-related psychological distress are recommended to be performed at least once a year. Level B requires anonymized data on well-being assessments to be given to individual clinicians and the IBD clinic. Action must also be taken at least once a year to address patient satisfaction of the clinic’s management of general well-being and disease-related psychological distress. Level A requires the clinic to assess any changes made to improve patient well-being within 1 year.

### Quality of Disease Management

Level D care delivery will have paper or electronic systems for recording IBD quality indicators and auditable outcomes. The list of indicators should be agreed upon as an acceptable standard of care, as defined by the IBD clinic. Level C IBD clinics must have an electronic health record to document and analyze care-related indicators. Further, a mechanism should exist to review the quality indicators and auditable outcomes annually, and outcomes

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**Table 3. Continued**

| Dimension: Quality of Patient Experience | Item | Statement | Level | Mean rating score, (1–5)* |
|---|---|---|---|---|
| | | Nutrition | | |
| | | | Enterostomal therapy | |
| | | | Pain management | |
| | | | Diagnostic testing including endoscopy and radiologic imaging | |
| 9.4 | | The IBD clinic wait times are reviewed and communicated to all IBD health care providers and the clinic staff, and are available in paper or electronic form | C | 4.3 |
| 9.5 | | The IBD clinic makes changes to reduce wait times if patients in any priority level have longer than acceptable wait times | B | 4.4 |
| 9.6 | | Actions to achieve agreed upon timelines for access to other clinical specialties and diagnostic services are undertaken | B | |
| 9.7 | | IBD clinic practitioners collaborate and, if necessary share resources, to facilitate prompt, appropriate access to care for IBD patients | B | |
| 9.8 | | The clinic reviews the effect of changes made to access to clinical and diagnostic services within 1 year | A | 4.3 |
| Ability to provide feedback | | | | |
| 10.1 | | The IBD clinic has a system for gathering patient feedback such as satisfaction surveys, focus groups or invited comments | D | 4.4 |
| 10.2 | | The IBD clinic has a policy for managing patient complaints that is available in paper and/or electronic form | D | |
| 10.3 | | Patient satisfaction surveys are performed at least once per year | C | 4.5 |
| 10.4 | | Action is planned (with auditable outcomes) in response to patient complaints and patient satisfaction surveys | B | 4.5 |
| 10.5 | | The IBD clinic has a person or committee responsible for reviewing complaints and patient satisfaction survey results | B | |
| 10.6 | | The clinic makes changes within 6 months to feedback elicited from patient satisfaction surveys and complaints | B | |
| 10.7 | | The IBD clinic reviews the impact of changes made to correct problems elicited from patient surveys and complaints within 1 year of adoption of an action plan | A | 4.5 |

*Based on a five-point Likert scale (1 = strongly disagree, 5 = strongly agree).
feedback must be given. Level B IBD clinics must have a plan of action with individual clinicians if their performance does not meet acceptable standards. A mechanism should also be in place to review and make recommendations to clinics or clinicians who do not meet performance standards and benchmarks after an agreed upon timeline. Level A is achieved if an IBD clinic reviews the impact of recommendations within 1 year.

**Appropriateness of Treatment and Investigation**

Obtaining Level D for appropriate treatments and investigations requires having agreed upon guidelines and standardized protocols. Guidelines for the use of specific therapies, investigations and for follow-up should be available in paper and/or electronic form. There should also be available guidelines for surveillance colonoscopy for dysplasia (46). Agreed upon standardized protocols should be implemented for monitoring disease activity and associated adverse events. It is recommended for the IBD clinic to have a defined protocol for managing the transition of care from paediatric to adult, and for managing special and vulnerable IBD populations. Level C can be achieved by establishing a mechanism to assess the proportion of patients undergoing surveillance colonoscopy according to the established guidelines. The IBD clinic must also perform annual audits of adherence to the guidelines and protocols, and IBD clinicians must receive the results. Level B facilities must have an action plan within 6 months of audit results if suboptimal performance is identified. Level A will review the impact of the changes within 1 year.

**Communicating Management Plans and Results**

For level D IBD clinics, response letters to the referring physicians must be sent within 10 working days of a clinic visit. A summary of pertinent changes to therapy, planned investigations and follow-up will be made available in the patient's chart. Copies of the relevant investigation reports will be circulated with clear communication as to who should act on the results. Level C facilities must establish standard reporting elements for communicating results and complete an annual quality of communication patient survey. Furthermore, annual audits of clinicians' adherence to standardized completion of clinic letters detailing the management plan should be performed. Level B is achieved if action is taken in response to communication assessments determined to be below the agreed upon standards. Annual audits of referring physicians are to be completed to assess the quality of how results and management plans are communicated. An action plan must be implemented within 6 months if problems are identified. Level A is achieved if the impact of the action plan is reviewed within 1 year.

**Dimension: Quality of Patient Experience**

**Access**

Access to care at level D requires a clinic to provide a contact number and/or e-mail address and specific information of all procedures to be scheduled before the patient leaves the clinic. It is also recommended that the IBD clinic provide patients with a mechanism for accessing urgent appointments or other care during periods of disease flare. The IBD clinic should have in place a mechanism to triage and return phone calls based on urgency and type of request. Level C can be achieved by conducting annual patient satisfaction surveys regarding communication and access to IBD clinics and information. Level B is achieved if actions are undertaken in response to patient surveys within 6 months. Level A requires the IBD clinic to review the impact of changes within 1 year of receiving the survey responses.

**Booking and Clinic Visit**

For IBD clinics at level D, there must be a process to confirm that patients are informed of their appointment; that sufficient and readily accessible patient toilet facilities are provided; that the scheduled time and actual start time of the clinic visits are recorded; and that no-show and cancellation rates are monitored with relevant factors noted. Improvements in these processes (level C) can be achieved if referring physicians and family physicians are notified of missed appointments. To reduce missed appointments, patients should receive a reminder prior to their appointment. In order to track clinic punctuality, the proportion of patients who are delayed in clinic should be recorded. Additionally, feedback should be elicited by an annual patient satisfaction survey. Level B requires the IBD clinics to respond to feedback with action plans within 6 months of receiving survey responses. The IBD clinic must also make changes if the no-show or cancellation rates exceed agreed upon acceptable rates, as defined by the IBD clinic. To attain level A, the IBD clinic should review the impact of changes, and the problems must be corrected within 1 year.

**Timeliness of Care**

An IBD clinic should establish formal criteria to prioritize new referrals as: urgent, semiurgent, routine or second opinion. There should also be documentation of wait times for consultations by priority level and to multidisciplinary specialty services (level D). To improve upon the timeliness of care (level C), the IBD clinic wait times must be reviewed and communicated, and made available in paper or electronic form. Level B is achieved if the IBD clinic makes changes to reduce wait times for patients; if actions to achieve agreed upon timelines for access to other specialties and diagnostic services are undertaken; and if collaboration occurs to facilitate prompt, appropriate access to care. Level A requires the IBD clinic to review the impact of changes made within 1 year.

**Ability to Provide Feedback**

A level D facility must have a system for gathering patient feedback. They should also have a policy for managing patient
complaints that is available in paper and/or electronic form. Level C can be attained if patient satisfaction surveys are performed at least once per year. Level B requires an action plan in response to patient complaints and satisfaction surveys. The IBD clinic should have a person or committee responsible for reviewing complaints and survey results. The subsequent changes must be made within 6 months of receiving this feedback. Level A requires review of the impact of changes made to correct problems within 1 year of adoption of an action plan.

Discussion

The development of the electronic IBD GRS self-reporting system has the potential to improve care for IBD patients by identifying metrics for quality improvement activities, promoting a constant reassessment of impact with interpretation of observed outcomes and strategies to achieve desired outcomes (34,35,40). This initiative targets all IBD service areas: offices, clinics and centres. The GRS also has the potential to optimize care by promoting best practices and reducing variation in care delivery. It has been proven to successfully create positive changes within a health care system, and this particular tool has been modified to be specifically impactful for the Canadian IBD health care system (32,33,47).

The strengths of this novel initiative were that it was modeled upon successful endoscopy-based GRS programs in the United Kingdom and Canada (31–37,48). Further, although this tool is specifically designed for IBD institutions and not for patient use, the statements established by patients for the IBD quality indicators provided essential content for the patient-related IBD GRS statements (38). Another strength of this initiative is that the IBD GRS will provide a conduit via surveys and formal assessments for ongoing patient evaluation and input into the quality of their IBD health care delivery. Use of available validated patient surveys may also serve to standardize and compare care across different clinical practices. The collaborative relationship with CAG and Crohn’s and Colitis Canada will allow for further knowledge dissemination of the tool and national uptake. Further, this is the first web-based self-assessment tool for IBD, which can be utilized by other countries to standardize and improve quality of care internationally.

This endeavour was limited by the paucity of high-quality literature available on IBD to inform the GRS statements. The statements were designed by experts in the field of IBD and evidence-based where possible. Therefore, the methodology behind the creation of the IBD GRS is less rigorous than the establishment of clinical practice guidelines. However, by standardizing quality improvement activities and decreasing variability of care processes, new evidence can be translated into practice in a timelier manner. Further, uptake may be limited by insufficient resources to utilize the IBD GRS. However, this was not the experience of the UK and Canadian endoscopy GRS. Furthermore, there is potential to encourage site participation by linking the IBD GRS to accreditations and or Royal College practice assessments to acknowledge growth in achievements on the scale. IBD is a lifelong chronic disease that requires constant delivery of care. As the incidence of the disease increases in North America and Europe, the IBD GRS will assist in the optimization of health care delivery and improve resources available for this patient population (15,17,20). This work will also allow others to assess the impact of quality measures and iteratively improve the GRS to further enhance care.

The IBD GRS will be made available to IBD clinics and health care professionals across Canada through the CAG web-based platform (37). As the first iteration of the IBD GRS, further work upon its validation and implementation will be required. The IBD GRS implementation phase will include a pilot test at the five Crohn’s and Colitis Canada PACE centres (39), and the seven Canadian IBD Network for Research and Growth in Quality Improvement (CINERGI) centres not affiliated with PACE (49), and at community IBD centres to assess feasibility and effectiveness. Analysis of surveys from these sites will help clarify and, if needed, adjust statements to be implemented in future iterations of the IBD GRS. A pilot validation study assessing the psychometric properties of the IBD GRS will also be conducted similar to what has been done for the C-GRS (36). Impact of the IBD GRS at pilot centres will be reported and, if positive, further knowledge translation activities will be undertaken to promote uptake nationally. Furthermore, this platform could be used, or serve as a template, by other countries to improve quality of IBD care.

We have developed the first IBD GRS that will be made available through the CAG web-based platform for IBD clinics and health care professionals across Canada in order to improve the quality of care for this patient population. Further plans to pilot and promote the adoption of the tool will be developed. The utilization of this electronic self-assessment tool will allow for the ongoing identification of gaps in care and the establishment of evaluation processes and timelines to improve IBD health care service delivery. The IBD GRS was created based on best available evidence and expert opinions. Further research is required in order to promote its adoption and evaluate the impact of this tool on the Canadian health care system and IBD patients.

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Conflicts of Interest and Source of Funding

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Author Contributions

A.B.: Contributed to the planning and conduct of the study, collecting and interpreting data, drafting the manuscript and approval of the final draft. K.S.D.: Contributed to the drafting of the manuscript and approval of the final draft. B.B., J.H., V.J., J.J., P.M., A.W.V., C.D. and D.M.: Contributed to the collection and interpretation of data and approval of the final draft. G.C.N., PACE network: contributed to the planning and conduct of the study, the collection and interpretation of data and approval of the final draft.

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