

Set (COS) is of great importance. We generally agree with their comments, of which most were acknowledged in our paper.

First, clinicians are key stakeholders when developing a COS for haemorrhoidal disease (HD), and inclusion of a representative sample of clinicians with relevant expertise is important. Initially, we contacted the 43 international representatives of the European Society of Coloproctology (ESCP) to participate in development of the COS. However, most representatives did not treat HD or felt that they were not experienced enough to provide input to the COS. Following their recommendations, we invited, using the so-called snowball method, health-care professionals with an in-depth understanding of HD and/or development of a COS to contribute. This strategy resulted in a smaller group of experts than initially planned, and we do consider this a limitation, which we acknowledged in the discussion section of our paper. However, the clinicians included still represented multiple European countries; in our opinion, and also the fact that no guidance exists regarding the minimum sample size of a stakeholder group, this approach produced valid views in an area in which experienced research professionals are limited.

Second, partial patient involvement in development of this first COS for HD was discussed as a limitation. Furthermore, a point highlighted in the title of our paper. Future editions of a COS for HD should indeed ensure a more prominent role of the patients.

Third, this COS focussed on a clinical research setting (i.e. clinical effectiveness studies) and for this reason we felt that it was appropriate (and consensus was reached) for use on core primary and secondary outcomes. We agree that in some contexts (a cost-effectiveness analysis, for example) other outcomes also may be relevant. We would like to emphasize that a COS represents the minimum set of outcomes to be collected in a clinical trial. Therefore, in our discussion we recommend that additional outcomes may be included if appropriate for the specific intervention or setting.

Finally, ideally one would follow the recommended methodology for selecting instruments for the outcomes of a COS [1]. However, the instruments selected for our COS were consensus-based and are the most widely used and validated instruments in the field. Uptake of a COS could be promoted by proposing it together with a suggestion for additional instruments.

Future work should address these issues to ensure a valid and relevant COS for HD. Hence, in our paper, we emphasized that a COS is a dynamic instrument and should regularly be reviewed.

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Comment on 'The Association of Coloproctology of Great Britain and Ireland consensus guidelines in surgery for inflammatory bowel disease'

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Dear Editor,

I represent the Patient Liaison Group working with the Association of Coloproctology of Great Britain and Ireland (ACPGBI) particularly on the topic of inflammatory bowel disease (IBD). I took great pleasure in reading through the recently published guidelines [1].

From a patient's perspective, the issue of the ACPGBI consensus guidelines on surgery for IBD is a wonderful indicator of the collaboration that exists, not only between surgeons sharing their knowledge and expertise, but also between the surgeons and the gastroenterologists. The IBD Surgical Guidelines have been commissioned by ACPGBI to sit alongside the review by the British Society of Gastroenterology of the medical guidelines for the measurement of IBD [2]. This collaboration is most reassuring for patients and may encourage them to discuss the possibilities and options of surgery, alongside medical interventions, when considering treatment for their IBD.

The method of choosing which guidelines to use was also thought through very carefully and only those who had consensus between the authors at a high level were included. The surgeons involved spanned a wide range of specializations within bowel surgery and are highly regarded within their field and their peers. Also included amongst the authors were members of the ACPGBI's Patient Liaison Group who were invited to read the document and comment where their experience or knowledge allowed and so patients can be assured that their voice has been heard in the setting out of the guidelines.

The guidelines are comprehensive, covering all topics and aspects from indications as to how to select the right procedure for the right patient, through technical details of that procedure and onwards to the long-term postoperative outcomes and management. They look at Crohn's disease; pouch surgery, intestinal failure; surgery for IBD in pregnancy; right through to the impact of medications on surgery. Whilst the document is full of technical and medical information, it is still accessible to patients who can perhaps feel more empowered to discuss the surgical options with their surgeon and ask for more explanation where needed.

As always, the access to knowledge and information often leads to more questions. These guidelines lead to the question: 'at what stage should or would the patient be ready for a discussion about surgical options?' Many of us struggling with long-term IBD put off this conversation until a rescue operation is indicated very soon, if not under emergency conditions. Perhaps the availability of these surgical guidelines will enable gastroenterologists and patients to broach the subject earlier in the course of the patient's illness.

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Ready for the National Accreditation Programs for Rectal Cancer? Auditing rectal cancer outcomes in the United States

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Dear Editor,

Roxburgh *et al.* performed a powerful institutional audit of their comprehensive cancer centre's locally advanced rectal cancer database [1]. We applaud the authors for continuing to reset the bar for treatment and outcomes in rectal cancer, embracing minimally invasive surgery, adopting new therapy strategies and technology to improve staging and the technical aspects

of the resections, and considering the patient's preferences in their work. Above all, we recognize their efforts to track the clinical and surgical management, and use these results to support changes in their practice and optimize patient care.

Their work is timely, with development of the National Accreditation Programs for Rectal Cancer (NAPRC) standards meant to measure and improve performance in the United States [2]. These standards aim to educate on precision surgery and multidisciplinary care, and improve clinical outcomes and technical quality measures. Studies have been performed at the institutional level, showing improvement in outcomes before and after implementation of these standards within a multidisciplinary tumour board [3,4]. As the NAPRC is implemented, the need for and enthusiasm about these standards at the institutional level has been demonstrated [5–7]. However, the ability to audit compliance with these standards for continuous quality improvement at the national level is unknown. There has been little work on evaluating the national state at baseline or identifying possible obstacles to success in the NAPRC process. In the United States, the National Cancer Database (NCDB), a clinical oncology database sourced from hospital registry data collected from Commission on Cancer (CoC)-accredited facilities, is the best tool with which to analyse, benchmark and track patients with malignant neoplastic diseases, their treatments and their outcomes [8]. We sought to assess the ability of the NCDB to support the audit and performance of the NAPRC. In short, is the NCDB sufficient to support the NAPRC efforts?

To this end, a review of the NCDB was carried out for all resections for rectal adenocarcinoma performed via an abdominal approach at CoC-participating hospitals from 2010 to 2015. The results were presented at the American Society of Colon and Rectal Surgeons 2019 Annual Meeting in June. Cases performed via a local excision and an endoscopic approach or which were missing data in the variables of interest were excluded. The demographic, staging, operative and oncological data were evaluated. The main outcome measures were the technical, process and quality measures compared with the published NAPRC standards. The secondary outcomes were the limitations in data capture and reporting with the database.

From the analysis, we found 73 363 cases that met inclusion criteria during the study period. The majority were men (60.7%) who received neoadjuvant chemoradiation (55.6%). From the clinical staging, 40.6% were T3 lesions and 42.2% node positive. Most patients lived within 0 to 20 miles of their treatment centre (66.1%).