

# DECIDE: Delphi Expert Consensus Statement on Inflammatory Bowel Disease Dysplasia Shared Management Decision-Making

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## Abstract

**Background and Aims:** Inflammatory bowel disease colitis-associated dysplasia is managed with either enhanced surveillance and endoscopic resection or prophylactic surgery. The rate of progression to cancer after a dysplasia diagnosis remains uncertain in many cases and patients have high thresholds for accepting proctocolectomy. Individualised discussion of management options is encouraged to take place between patients and their multidisciplinary teams for best outcomes. We aimed to develop a toolkit to support a structured, multidisciplinary and shared decision-making approach to discussions about dysplasia management options between clinicians and their patients.

**Methods:** Evidence from systematic literature reviews, mixed-methods studies conducted with key stakeholders, and decision-making expert recommendations were consolidated to draft consensus statements by the DECIDE steering group. These were then subjected to an international, multidisciplinary modified electronic Delphi process until an a priori threshold of 80% agreement was achieved to establish consensus for each statement.

**Results:** In all, 31 members [15 gastroenterologists, 14 colorectal surgeons and two nurse specialists] from nine countries formed the Delphi panel. We present the 18 consensus statements generated after two iterative rounds of anonymous voting.

**Conclusions:** By consolidating evidence for best practice using literature review and key stakeholder and decision-making expert consultation, we have developed international consensus recommendations to support health care professionals counselling patients on the management of high cancer risk colitis-associated dysplasia. The final toolkit includes clinician and patient decision aids to facilitate shared decision-making.

**Key Words:** Inflammatory bowel disease; dysplasia management; decision-making

## 1. Introduction

Inflammatory bowel disease [IBD] is a recognised risk factor for colorectal cancer development,<sup>1</sup> but despite the adoption of colonoscopic surveillance, mortality remains higher with colitis-associated cancer compared with sporadic cancers.<sup>2</sup> Although most visible dysplasia can now be resected endoscopically, there remains a role for cancer-preventive, prophylactic colectomy in cases where the dysplasia is endoscopically unresectable or the future risk of cancer is high. Clinician uncertainty regarding the long-term prognosis of dysplasia<sup>3,4</sup> and patients' understandable reluctance to accept life-changing surgery,<sup>5-8</sup> particularly when they are in clinical remission, make counselling these patients challenging. International society guidelines strongly advocate multidisciplinary discussions about the management of dysplasia to be individualised to the patient, taking into consideration their personal preferences.<sup>9-12</sup> Shared clinician-patient decision-making is particularly important when the evidence and best management option are unclear and there are potentially harmful consequences associated with the choice that is eventually made.<sup>13-15</sup> On average, IBD patients will only consider having a colectomy if their risk of having a colorectal cancer at that time point is 49% or greater.<sup>5-8</sup> In addition, IBD patients are reassured by having surveillance<sup>6,16</sup> despite high post-colonoscopy colorectal cancer rates.<sup>17</sup> A UK survey study examining how IBD patients wish to be counselled about the management of dysplasia found that a substantial proportion [29%] of the dysplasia-experienced participants did not feel well informed about the associated cancer risk and/or its management by their clinical team.<sup>8</sup> An international clinician survey has also revealed divergence in colitis-associated dysplasia cancer risk perceptions and management practice, with a reluctance to recommend a proctocolectomy to patients despite a diagnosis of higher-risk endoscopically unresectable low-grade dysplasia [LGD].<sup>3</sup>

The objective of the DECIDE steering group was to develop expert consensus-derived standards for health professionals

[gastroenterologists, colorectal surgeons, and IBD/pouch/stoma specialist nurses] who counsel patients with colitis-associated dysplasia about their surgical or endoscopic management options. The aim of this consensus guidance is to optimise and standardise the quality of information given to patients and to encourage shared decision-making. It also informs the content of decision aids for both patients and health professionals which are to be used to support more confident decision-making [Supplementary Appendices 4 and 5].

## 2. Materials and Methods

The target population for the statements are adult IBD patients who are diagnosed with colitis-associated dysplasia and are at a higher risk of progression to cancer. These consensus standards were developed according to Grading of Recommendations Assessment, Development, and Evaluation [GRADE] methodology<sup>18</sup> and in accordance with the principles of the AGREE II tool.<sup>19</sup> There were three phases to the consensus standards development.

### 2.1. Phase 1. Systematic literature reviews

The strategies used to search the Medline, EMBASE, Cochrane, and APA PsycInfo databases for articles have been included in the [Supplementary Appendix 1](#). Article reference lists were additionally hand-searched. Systematic reviews and the highest-quality studies or studies reflective of endoscopic/surgical practice in the past two decades were prioritised for inclusion in the evidence narrative summaries.

### 2.2. Phase 2. Key stakeholder consultation

Mixed-method survey and interview studies involving key stakeholders were undertaken to explore their lived experiences, dysplasia risk perceptions, management preferences, and information communication preferences when counselling or being counselled about the management of

colitis-associated dysplasia. Ethical approval was granted [Central Berkshire Research Ethics Committee, REC reference no. 18/SC/0466, and the Health Research Authority and the Health and Care Research Wales bodies]. All participants gave informed consent. UK IBD colitis patients [ $n = 123$ ] who were in a surveillance programme or had had a dysplasia diagnosis participated in a survey that has been previously published,<sup>8</sup> and/or participated in audio-recorded semi-structured individual interviews [ $n = 25$ ] with thematic analysis of the interview transcripts.<sup>20,21</sup> A survey of international IBD clinicians [ $n = 294$ ] has also previously been published.<sup>3</sup> The findings from these studies, together with recommendations by the DECIDE steering group [three colorectal surgeons, three gastroenterologists, and an IBD/pouch/stoma specialist nurse] and a health psychologist with expertise in decision-making and risk communication, informed the content of the drafted consensus statements.

### 2.3. Phase 3. Delphi voting rounds

A modified electronic Delphi technique<sup>22</sup> was used to develop the consensus statements further. Candidates were recruited to the international Delphi expert panel through snowball and purposive sampling. Invitations were advertised via the clinician surveys distributed to members of the British Society of Gastroenterology [BSG] IBD and colorectal sections, the European and Crohn's and Colitis Organisation<sup>3</sup> and via social media. Consensus panel eligibility was based on specific criteria detailed in [Supplementary Table 1](#). The draft consensus statements and evidence narrative syntheses generated from Phases 1 and 2 were presented to the panel electronically. Agreement with the draft consensus statements was voted anonymously through multi-iterative online voting rounds at 4-week intervals. The participants were asked to indicate their level of agreement with each consensus statement using a five-point Likert scale: strongly agree [A+], agree with minor reservation [A], undecided [U], disagree [D], strongly disagree [D+]. They were invited to provide comments, propose additional supportive evidence [own data/grey literature/guidelines], and make suggestions for statement modification. The steering group coordinators modified the statements based on the feedback before re-distribution to the consensus panel for voting. Voting rounds were suspended once there was 80% or more agreement [A+/A] between panel members. GRADE methodology<sup>18</sup> has been used to indicate the strength of the recommendation, where a 'strong recommendation' reflects that the panel is confident that the desirable effects of an action outweigh the undesirable effects, and a 'weak recommendation' reflects that there is uncertainty in the balance. The level of agreement with each statement is described as the percentage of the panel that voted in agreement [A+/A]. The quality of evidence for each final agreed statement has been ranked also using GRADE methodology<sup>18</sup> as agreed by the consensus panel members [[Supplementary Table 2](#)].

## 3. Results

A total of 31 members from nine countries formed the Delphi international expert consensus panel. Two iterative anonymous voting rounds were conducted before >80% consensus agreement [A+/A] for each of the 18 statements was achieved. In the final voting round, 30 of the 31 Delphi panel members responded. Details of the members of the DECIDE steering group and the Delphi consensus panel have been

**Table 1.** Summary of Delphi panel member demographics.

Delphi panel member demographics	N = 31
<b>Clinical role</b>	
-Colorectal surgeon	14
-Gastroenterologist	15
-IBD/pouch/stoma nurse specialist	2
<b>Country of origin</b>	
-Australia	2
-Belgium	1
-Canada	1
-Greece	2
-Italy	2
-The Netherlands	1
-Sweden	1
-Turkey	1
-United Kingdom	20
<b>Workplace affiliation</b>	
-Tertiary/academic hospital	26
-Secondary/general hospital	5

included in [Supplementary Table 4](#) and summarised in [Table 1](#). The final consensus statements are listed in [Table 2](#) and a narrative summary of the supporting evidence for the statements follows.

### 3.1. Dysplasia patient risk stratification and management

International consensus dictates that surveillance colonoscopy can be continued after endoscopically visible dysplasia has been fully resected and there is no other unresectable dysplastic change in the colonic mucosa.<sup>9-11,23</sup> The pooled estimated cancer incidence after endoscopic resection of polypoid dysplasia in ulcerative colitis [UC] patients on surveillance follow-up [ $n = 376$ ] in a meta-analysis was low at 0.5 cases per 100 patient-years.<sup>24</sup> A multicentre cohort study of UC patients [ $n = 460$ ], who had surveillance follow-up for a median 4.1 years after a low-grade dysplasia [LGD] diagnosis, calculated incidences of advanced neoplasia (high-grade dysplasia [HGD] and cancer) after endoscopic resection of unifocal polypoid and non-polypoid dysplasia to be 0.7 (95% confidence interval [CI] 0.3–1.3) and 2.5 [95% CI 1.2–4.7] cases per 100 patient-years, respectively.<sup>25</sup> The lowest rates of progression to advanced neoplasia are reported by studies where high-definition imaging and/or chromoendoscopy surveillance have been used and *en bloc* endoscopic resection has been histologically confirmed with clear [R0] resection margins.<sup>4,26</sup>

Larger and non-polypoid colitis-associated dysplastic lesions are particularly difficult to resect fully due to the underlying inflammation-induced submucosal fibrosis.<sup>27</sup> Endoscopists and endoscopy centres with higher-volume experience in polypectomy have greater reported R0 resection rates and lower post-colonoscopy colorectal cancer rates.<sup>17,28,29</sup> Therefore, it is recommended that these lesions are resected by endoscopists with advanced polypectomy expertise in endoscopic mucosal resection [EMR], endoscopic submucosal dissection [ESD], or hybrid techniques. Not all

**Table 2.** DECIDE consensus panel recommendations on the management and counselling of patients with colitis-associated dysplasia

Statements	A+/A %	Grade	
		SoR	QoE
1. We recommend that all patients diagnosed with colitis-associated dysplasia be discussed in a multidisciplinary team meeting to achieve consensus on the future recommended management and ensure documentation. To achieve a quorate meeting, attendance of at least one gastroenterologist and one colorectal surgeon is required, including an endoscopist with expertise in advanced therapeutic or IBD surveillance colonoscopy and optical characterisation of advanced colonic lesions.	100%	Strong	Low
2. We recommend that unifocal colitis-associated dysplasia that has been successfully endoscopically resected can be managed with continued surveillance, performed by an experienced IBD endoscopist using high-definition white light and image-enhanced endoscopy. However, these patients should still be counselled about their long-term risk of metachronous advanced neoplasia and how this risk can be mitigated.	96.7%	Polypoid LGD: Strong	Low
		Non-polypoid dysplasia/HGD: Weak	Very low
3. We suggest that a patient with colitis-associated visible dysplasia is referred to a regional endoscopy centre with expertise in advanced polypectomy if: [i] there is uncertainty about the endoscopic resectability of the lesion despite local expertise; [ii] there are no macroscopic features suggestive of submucosal invasion; [iii] the patient gives consent.	96.7%	Weak	Very low
4. We recommend that patients with colitis-associated dysplasia who are at a higher risk of cancer development and are appropriate surgical candidates, should be counselled carefully about the benefit of prophylactic colectomy over continued surveillance. High cancer risk factors include presence of at least one of the following: [i] lesion-specific characteristics, eg, high-grade dysplasia, large non-polypoid morphology, multifocal, invisible or endoscopically unresectable dysplasia,;and [ii] patient-specific risk factors, eg, previous dysplasia, primary sclerosing cholangitis, active colonic inflammation, colonic stricture, or family history of colorectal cancer.	100%	Strong	Low
5. We suggest that patients with higher-risk colitis-associated dysplasia who need to be counselled about surgery have a joint consultation with a gastroenterologist and colorectal surgeon. Clinics may ideally be coordinated to run as a combined multidisciplinary clinic or in parallel clinics to facilitate this and include a specialist nurse with expertise in IBD and/or stoma and pouch care.	100%	Weak	Very low
6. We recommend that the principles of shared decision-making are used when counselling patients about the risks and benefits of endoscopic or surgical management of colitis-associated dysplasia. Numerical and individualised risk estimates should be communicated where possible. If there is uncertainty due to low-quality data and an individualised risk cannot be given, then information about their risk factors comparative with an IBD patient without risk factors can facilitate risk comprehension.	100%	Strong	Very low
7. We suggest that patients with higher-risk colitis-associated dysplasia are made aware of their alternative management options, the associated risks and benefits, and whether these are suitable in their case. a. Enhanced endoscopic surveillance and management, or: b. surgical management: [i] panproctocolectomy and permanent ileostomy; [ii] restorative proctocolectomy with ileoanal pouch formation; [iii] less extensive and rectum-preserving surgery in selected cases [eg, ileorectal anastomosis or segmental colectomy]; or c. no surgery nor endoscopic management.	96.7%	Weak	Very low
8. We recommend that patients are informed of the risks and benefits of continued colonoscopic surveillance after a dysplasia diagnosis. The benefits may be that: [i] surgery is avoided in the short term, particularly for those with a high risk of peri-operative complications; and [ii] current bowel function may not change if their colitis remains quiescent. The risks may include: [i] need for more frequent colonoscopies and polypectomies with their associated risks of bleeding and perforation; [ii] continued long-term risk of developing active colitis requiring medical therapy or surgery; [iii] continued long-term risk of developing a cancer due to the limitations of surveillance. When detected, these cancers may be at an advanced stage and associated with a poorer prognosis and therefore may require more extensive surgery, chemotherapy, and/or radiotherapy.	100%	Risk of cancer despite surveillance: Strong	Moderate
		Patient-reported outcomes: Strong	Very low
9. We recommend that patients being counselled about surgery are informed of their operative morbidity and mortality risks, based on their comorbidities, functional status, and institutional data. Shorter-term general complications may include wound healing delays, anastomotic leak, infections, venous thrombosis, bleeding, and small bowel obstruction or ileus. Most can be treated medically but some will require re-operation. Mortality is low [ $<1\%$ risk]. A role for laparoscopic or less extensive colectomy surgery, which carry the lowest complication risks, may be discussed if the expertise is available and the patient is an appropriate candidate.	90%	Mortality: Strong	Moderate
		General complications: Strong	Low
10. We recommend that patients being counselled about a proctocolectomy, should be informed of further potential complications associated with the pelvic dissection required for a proctectomy: [i] sexual dysfunction: erectile or ejaculatory dysfunction can occur in 3% or less of men postoperatively but this is least likely in men younger than 50 years and is often treatable with medical therapy. More women may experience dyspareunia postoperatively. However, overall long-term sexual function and satisfaction do not deteriorate in the majority of both men and women postoperatively; [ii] reduced fecundity, ie, a reduced ability to conceive during a period of unprotected sexual intercourse. However, this risk may be lower after laparoscopic surgery compared with open surgery; the negative implications of uncontrolled inflammatory disease on sexual function and fecundity should also be discussed.	100%	Sexual function: Strong	Low
		Fecundity: Strong	Very low

Table 2. Continued

Statements	A+/A %	Grade	
		SoR	QoE
<p>11. We recommend that patients being counselled about a panproctocolectomy and permanent ileostomy, should be informed of the potential advantages and disadvantages over other surgical options.</p> <p>The advantages to be considered are that:</p> <ul style="list-style-type: none"> <li>[i] complete removal of colonic and rectal tissue will eliminate any further risk of colorectal cancer or colitis-associated symptoms [although Crohn's patients may get recurrence at other sites];</li> <li>[ii] surgery can be performed in one operative stage electively;</li> <li>[iii] stomas can allow better bowel control than a pouch in some cases. Overall quality of life has been shown to be high postoperatively and similar to pouch surgery patients.</li> </ul> <p>The disadvantages to be considered are:</p> <ul style="list-style-type: none"> <li>[i] stoma-related complications [20–30% risk of a re-do operation over 10 years; risk highest in Crohn's patients];</li> <li>[ii] the possible impact of a permanent stoma on body image, diet, and work/social function;</li> <li>[iii] the potential negative impact of a proctectomy on sexual function and fecundity.</li> </ul>	100%	Patient-reported outcomes and stoma-related complications:	Strong Low
<p>12. We recommend that patients being counselled about a restorative proctocolectomy with ileoanal pouch anastomosis, are informed of the following potential advantages and disadvantages over other surgical options.</p> <p>The advantages to be considered are that:</p> <ul style="list-style-type: none"> <li>[i] removal of all colonic and most of the rectal tissue will significantly diminish future risk of colorectal cancer; and</li> <li>[ii] they may have improved colitis-associated symptoms, if they have active and uncontrolled disease pre-operatively;</li> <li>[iii] it allows the maintenance of bowel evacuation via the anus and avoidance of a permanent stoma in most cases.</li> </ul> <p>The potential disadvantages to be considered are:</p> <ul style="list-style-type: none"> <li>[i] this operation may not be suitable for selected individuals due to higher complication rates. Pouch surgery is not recommended for patients with impaired anal sphincters, perianal disease, or low rectal neoplasia. Patients with Crohn's colitis or primary sclerosing cholangitis should be informed of the elevated complication rates associated with pouch surgery in these groups;</li> <li>[ii] the need for two or three stages of operations and therefore a longer recovery time;</li> <li>[iii] the operation may not be offered at their local hospital and therefore may require longer-distance travel;</li> <li>[iv] they may experience symptoms from their pouch that are more troublesome than what they are currently experiencing [normal pouch function is 3–8 times a day, with the additional risk of problems, eg, pouchitis]. This may have an impact on their diet and work/social function;</li> <li>[v] the potential negative impact of pouch surgery on sexual function and fecundity;</li> <li>[vi] although the absolute risk of pouch cancer is low [<math>&lt;1\%</math> at 10 years postoperatively], prior neoplasia is associated with up to a 9-fold relative increased risk. Therefore, these patients would be recommended to have a yearly surveillance pouchoscopy.</li> </ul>	93.3%	Pouch function and complications:	Strong Low
<p>13. We suggest that in some selected cases of colitis-associated dysplasia less extensive surgery, such as total or subtotal colectomy with ileorectal anastomosis or segmental colectomy with primary anastomosis, may be considered. These selected cases may include patients with a higher operative risk [due to older age or multiple comorbidities], or are younger and have concerns about maintaining fecundity and sexual function, or they have segmental Crohn's colitis. They would need to have rectal sparing of inflammation and dysplasia, and normal anal sphincter function and rectal compliance.</p> <p>The potential advantages are that these less extensive surgeries are:</p> <ul style="list-style-type: none"> <li>[i] likely to be associated with a reduced cancer risk compared with continued surveillance due to removal of the affected part of the colon;</li> <li>[ii] they allow the maintenance of bowel evacuation via the anus and avoidance of a stoma;</li> <li>[iii] they can be completed in one operative stage;</li> <li>[iv] they do not require extensive pelvic dissection, minimising the risk of sexual dysfunction or reduced fecundity.</li> </ul> <p>The potential disadvantages are:</p> <ul style="list-style-type: none"> <li>[i] active inflammation recurrence in the colonic or rectal remnant left <i>in situ</i> may occur, requiring an escalation in medical therapy and potentially further bowel resection if medically refractory;</li> <li>[ii] patients may experience more urgency after an ileorectal anastomosis, but frequency and continence are normally better than experienced with ileoanal pouches;</li> <li>[iii] a greater cancer risk will exist compared with those who choose proctocolectomy surgery, which will require ongoing annual endoscopic surveillance with its attendant limitations [highest risk after segmental colectomy; reported as high as 25% cancer risk over 10 years if subtotal colectomy with ileorectal anastomosis for pre-operative dysplasia]. Cancers being diagnosed at an advanced stage would be associated with a poorer prognosis and may require more extensive surgery and oncological therapy.</li> </ul>	90%	Patient-reported outcomes:	Weak Low
<p>14. We recommend that patients with colitis-associated dysplasia who decline surgical or endoscopic management should be informed of their risk of developing colorectal cancer. In the short term they may avoid disruption to their quality of life from these interventions. However, if they develop cancer in the future, their quality of life will likely be reduced by more advanced disease requiring significantly more aggressive oncological interventions.</p>	100%	Strong	Very low
<p>15. We recommend that patients with colitis-associated dysplasia who are considering surgery, should meet with a specialist nurse to discuss stoma and pouch care and the likely impact of these on quality of life.</p>	100%	Strong	Very low
<p>16. We suggest that patients with colitis-associated dysplasia who are considering surgery are signposted to patient support groups or charities and be given the opportunity to speak to other patient advocates about life with a stoma or pouch, in order to support their decision-making.</p>	93.3%	Weak	Very low
<p>17. We recommend that patients with colitis-associated dysplasia, who are deciding between continued endoscopic management or colectomy, be given time to consolidate information, deliberate, and ask any further questions of their clinical team after the initial consultation. Use of a visual decision aid [leaflet, video, or online material] to facilitate this is encouraged.</p>	96.7%	Strong	Moderate
<p>18. We recommend that these patients be offered a second consultation, with ideally the same clinicians, if they have not made a decision after the first joint consultation. Any gaps in understanding and further queries should be addressed, and the consultation should conclude with an informed preference-based decision by the patient.</p>	100%	Strong	Very low

\*A+/A %, % level of agreement; SoR, strength of recommendation; QoE, quality of evidence; IBD, inflammatory bowel disease; HGD, high-grade dysplasia; LGD, LOW-LGD, low-grade dysplasia.

endoscopists who perform IBD surveillance have this specialist expertise.<sup>30</sup> Therefore, if the expertise is not available locally, referral to a regional therapeutic endoscopist or endoscopy centre is suggested. Although most reported advanced neoplasia rates after endoscopic resection of non-polypoid dysplasia from specialist therapeutic endoscopy centres have been low,<sup>4</sup> case series where ESD of large [ $>2$  cm] lesions have resulted in variable R0 resection success rates have still demonstrated progression rates to cancer of 22–40% with LGD and 50% with HGD.<sup>31,32</sup>

Careful optical characterisation of lesions at endoscopy is required to determine the likelihood of successful *en bloc* resection. Visible dysplasia that is endoscopically unresectable is a significant risk factor for cancer and should be managed with surgical resection rather than continued surveillance.<sup>9–12</sup> Lesions are unlikely to be successfully endoscopically resected if the borders of the lesion are non-delineated or there are features of submucosal invasion or significant submucosal fibrosis such as irregular surface architecture, mucosal depression, converging mucosal folds, or failure to lift with submucosal injection.<sup>33</sup> In any case of doubt, careful photo or video documentation and discussion together with careful placement of a tattoo should be followed by discussion at a multidisciplinary team [MDT] meeting either locally or at a regional centre. Previous expert consensus-derived standards of care have advocated MDT meetings as an important aspect of general IBD patient care.<sup>34–37</sup> To achieve a quorate meeting, attendance of at least one gastroenterologist and one colorectal surgeon is required, including an endoscopist with expertise in advanced therapeutic or IBD surveillance colonoscopy and optical characterisation of advanced colonic lesions. Inclusion of the latter would allow prompt decisions to be made on the suitability of a dysplastic lesion for endoscopic or surgical management locally or regionally. The panel also recognises the importance of a gastrointestinal histopathologist's role within the MDT and the requirement for two expert histopathologists' confirmation of a dysplasia diagnosis.<sup>9–11</sup> The consensus panel encourages that all patients diagnosed with colitis-associated dysplasia, even if resected at endoscopy, are discussed at an MDT meeting to facilitate a more holistic consideration of the patient's future cancer risk when decision-making. The MDT discussion should recognise the implications of other co-existent cancer risk factors [eg, primary sclerosing cholangitis], or where effective continued surveillance is difficult [eg, active inflammation, extensive post-inflammatory mucosal change, or strictures], and confirm future surveillance intervals or need for surgical consideration. Clinician survey studies have shown variation in dysplasia management practice, demonstrating that gastroenterologists may be less likely to advocate colectomy for high-risk dysplasia than colorectal surgeons<sup>38</sup> or if they work in a non-tertiary care centre, which may be a result of decreased access to specialist MDT meetings.<sup>3</sup> A theme derived from the interviews conducted with the DECIDE patient stakeholders was that patients were more likely to trust their clinician's management recommendations, despite the uncertainty in their cancer risk, if they knew that there was MDT-based peer consensus [Supplementary Appendix 2].

Patients should be made aware of their continued long-term risks of metachronous advanced neoplasia despite endoscopic resection of dysplasia and surveillance follow-up. Colitis-associated cancers appear to display molecular characteristics which confer a more aggressive phenotype compared with

sporadic cancers.<sup>39–42</sup> Occult clonal evolution of neoplasia-promoting genetic changes in colitis is detectable throughout the entire colon long before the development of clinically detectable neoplasia, indicative of a 'field cancerisation' effect, which may explain the increased incidence of multifocal synchronous and metachronous cancers in IBD.<sup>39,40</sup> Patients should be counselled about how they can mitigate their own cancer risk. This includes complying with medications to optimise disease control, adhering to scheduled surveillance intervals and bowel preparation instructions for effective surveillance.<sup>43</sup> Patients should be counselled about any additional risk factors [Table 3] they may have which places them in a higher cancer risk category and where the benefit of prophylactic colectomy may now supersede long-term endoscopic surveillance. This is particularly the case if a patient has more than one risk factor, as the risk of advanced neoplasia appears to increase cumulatively with each additional risk factor.<sup>25,44</sup>

Invisible and endoscopically unresectable HGD is associated with a high risk of cancer and therefore recommendation for colectomy in this cohort is justified.<sup>45,46</sup> There remains some equipoise in international guidelines as to the best management of invisible LGD, due to the lower quality of evidence available and the acceptance that many of the 'invisible' lesions detected in historical studies likely would have been visible using modern-day high-definition and chromoendoscopic imaging by an experienced endoscopist.<sup>47,48</sup> Therefore, the incidence of synchronous cancers detected in colectomy specimens resected for a preoperative diagnosis of invisible LGD are much lower in the more modern era [Table 3]. Some may find it acceptable for a patient with unifocal invisible LGD to undergo a period of intensive and high-quality surveillance, rather than proceed immediately to colectomy.<sup>33</sup> However, patients should be made aware that the long-term data on invisible dysplasia are of low quality, mainly due to the inclusion of small numbers.<sup>4,49</sup> Multivariate analyses have shown that invisible morphology is an independent predictor of LGD progression to advanced neoplasia [Table 3], with a 2–3-fold increased long-term risk.<sup>25,49</sup>

### 3.2. Initial consultation with patients with high risk colitis-associated dysplasia

Patients with colitis-associated dysplasia and one of the risk factors detailed in Table 3 are at a high risk of developing cancer in the longer term. If they are an appropriate surgical candidate based on their age and comorbidities, it would be prudent to counsel these patients of the benefits of prophylactic surgery as an alternative management to continued colonoscopic surveillance. There was panel consensus that this consultation would ideally take place in a clinic setting with the core members of the MDT all jointly present, namely a gastroenterologist, a colorectal surgeon, and an IBD and/or a stoma and pouch care specialist nurse. Access to both surgical and gastroenterologist expertise at the same time for patients considering surgical or medical management is advocated by UK IBD standards of care<sup>12,36</sup> and preferred by patients,<sup>50,51</sup> including the DECIDE patient stakeholders who felt that it would increase decision-making confidence [Supplementary Appendix 2]. Initial discussions about surgery are often with the patient's gastroenterologist and framed as 'a last resort'.<sup>52–55</sup> Therefore, earlier introduction of surgery as an alternative treatment option, framed in more positive terms, has been advocated to enable more informed decision-making.<sup>54,56</sup> Although consultations would

**Table 3.** Clinical patient and lesion-specific risk factors for advanced neoplasia progression after a dysplasia diagnosis

Risk factors	Risk of progression to advanced neoplasia*
Primary sclerosing cholangitis	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Meta-analysis,<sup>49</sup> OR 3.4 [95% CI 1.5–7.8; 3 studies]</li> <li>• Univariate analysis, Dutch and USA multicentre cohort,<sup>179</sup> HR 2.5 [95% CI 1.2–5.3; <i>n</i> = 355]</li> </ul>
Previous dysplasia	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Belgian multicentre cohort,<sup>180</sup> RR 6.99 [95% CI 1.5–31.8; <i>n</i> = 410]</li> </ul> Indefinite for dysplasia progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Multivariate analysis of UK cohort,<sup>44</sup> HR 2.8 [95% CI 1.2–6.5; <i>n</i> = 172]</li> </ul>
Increased colonic inflammatory burden	UK multicentre cohort study, <sup>25</sup> cumulative inflammatory burden or recent [past 5 years] of moderate–severe active histological inflammation independently predicts LGD progression to advanced neoplasia, HR 3.1 [95% CI 1.5–6.7; <i>n</i> = 248]
Presence of a colonic stricture	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Multivariate analysis of Belgian multicentre cohort,<sup>180</sup> RR 2.64 [95% CI 1.00–6.96; <i>n</i> = 410]</li> <li>• Univariate analysis in UK cohort,<sup>44</sup> HR 7.4 [95% CI 2.5–22.1; <i>n</i> = 172]</li> </ul>
Patient demographics	LGD progression to advanced neoplasia, multivariate analysis Dutch population-based cohort <sup>181</sup> : <ul style="list-style-type: none"> <li>• Age 55 years or more, HR 1.7 [95% CI 1.4–2.1; <i>n</i> = 4284]</li> <li>• Male sex, HR 1.3 [95% CI 1.1–1.6; <i>n</i> = 4284]</li> </ul>
Family history of colorectal cancer	Found to be an independent risk factor associated with a 2–4-fold increase in cancer incidence in IBD population-based and multicentre cohort studies, <sup>182,183</sup> although not a significant independent factor for advanced neoplasia progression in established dysplasia <sup>180</sup>
Multifocal dysplasia	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Meta-analysis,<sup>49</sup> OR 3.5 [95% CI 1.5–8.5; 3 studies]</li> <li>• Multivariate analysis of UK cohort,<sup>25</sup> HR 2.9 [95% CI 1.3–6.2; <i>n</i> = 248]</li> </ul>
Endoscopically unresectable or incompletely resected dysplasia	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• Multivariate analysis of UK multicentre cohort,<sup>25</sup> HR 3.4 [95% CI 1.6–7.4; <i>n</i> = 246]</li> <li>• HGD/cancer incidence<sup>25</sup> = 5.2 per 100 patient-years [95% CI 1.9–11.5] if unifocal LGD</li> <li>• HGD/cancer incidence<sup>25</sup> = 19.3 per 100 patient-years [95% CI 10.5–32.8] if multifocal LGD</li> </ul>
Visible HGD	Synchronous cancer rate in colectomy specimen soon after pre-operative visible HGD: <ul style="list-style-type: none"> <li>• Historically associated with high rates of synchronous cancer [as high as 45%]<sup>165,184–186</sup></li> <li>• More recent studies from the videoendoscopic high-definition imaging era have suggested lower but still significant rates.<sup>4,46,187</sup> Pooled synchronous cancer rate = 13.7% [95% CI 0.0–54.1; <i>I</i><sup>2</sup> &gt;50%; <i>n</i> = 126; 3 studies; GRADE quality of evidence considered very low]<sup>4</sup></li> </ul> Colorectal cancer progression rate despite surveillance after endoscopic resection of HGD: <ul style="list-style-type: none"> <li>• Systematic review<sup>4</sup>: 0–40% after a median of 4 years if polypoid morphology and up to 50% after a median of 11 years if non-polypoid morphology</li> <li>• Belgian retrospective multicentre cohort<sup>180</sup> [where half of the lesions were non-polypoid, and 85% were endoscopically resected]: 14.8% [<i>n</i> = 4/27] developed a cancer over median follow-up of 6.4 years [IQR 3.8–9.9]</li> </ul>
Invisible HGD	Synchronous cancer rate in colectomy specimen soon after pre-operative visible HGD <sup>4</sup> : <ul style="list-style-type: none"> <li>• Pooled synchronous cancer rate = 11.4% [95% CI 4.6–20.3%; <i>n</i> = 69; 2 studies; GRADE quality of evidence considered very low].</li> </ul> Colorectal cancer progression rate despite surveillance after invisible HGD diagnosis: <ul style="list-style-type: none"> <li>• Cleveland clinic cohort<sup>45</sup>: 27.3% [<i>n</i> = 6/22] progressed to cancer after only a median follow-up time of 6.8 months</li> </ul>
Large diameter, non-polypoid dysplasia	LGD progression to advanced neoplasia: <ul style="list-style-type: none"> <li>• UK multicentre cohort multivariate analysis,<sup>25</sup> lesion diameter of 1 cm or more, HR 2.7 [95% CI 1.2–5.9; <i>n</i> = 246] regardless of whether lesions fully endoscopically resected or not</li> <li>• UK single-centre cohort multivariate analysis [<i>n</i> = 172],<sup>44</sup> non-polypoid morphology HR 8.6 [95% CI 3.0–24.8] compared with polypoid morphology, but not adjusted for resection status</li> <li>• Belgian multicentre cohort [<i>n</i> = 410],<sup>180</sup> non-polypoid morphology RR 13.8 [95% CI 3.1–61.2] compared with polypoid morphology, but not adjusted for resection status</li> </ul> Most case series reporting on ESD or hybrid techniques performed in specialist centres for large non-polypoid dysplastic lesions imply good prognoses if clear resection margins are achieved and these patients are followed up closely with high-quality surveillance. <sup>4</sup> However, small populations and limited follow-up times and some with low R0 resection rates report high progression rates to cancer [22–40% with LGD and 50% with HGD] <sup>31,32</sup>
Invisible LGD	<ul style="list-style-type: none"> <li>• Meta-analysis,<sup>4</sup> pooled estimated synchronous cancer rate = 2.4% [95% CI: 0.0–8.5%; <i>I</i><sup>2</sup> &gt;50%; <i>n</i> = 208; 3 studies; GRADE quality of evidence considered very low] compared with a more historical pooled analysis [22%; <i>n</i> = 18/81; 10 studies]<sup>188</sup></li> <li>• Multivariate analyses: invisible morphology is an independent predictor of LGD progression to advanced neoplasia, with a 2–3-fold increased risk in the longer-term<sup>25,49</sup></li> <li>• Data from the most recent studies where high-definition imaging and/or chromoendoscopy routinely used for surveillance follow-up have shown conflicting results<sup>25,47</sup>: <ul style="list-style-type: none"> <li>– Dutch multicentre cohort surveillance study,<sup>47</sup> 3.8% [<i>n</i> = 1/26] with invisible LGD developed cancer over a median of 5 years follow-up</li> <li>– UK multicentre UC cohort study,<sup>25</sup> cancer incidence for unifocal invisible LGD = 4.3 per 100 patient-years [95% CI 1.9–8.6; <i>n</i> = 7/42]</li> </ul> </li> </ul>

HGD, high-grade dysplasia; LGD, low-grade dysplasia; OR, odds ratio; HR, hazard ratio; RR, relative risk; CI, confidence interval; ESD, endoscopic submucosal dissection; IQR, interquartile range; IBD, inflammatory bowel disease; UC, ulcerative colitis.

ideally occur in either a dedicated combined/joint medical-surgical clinic or clinics that run in parallel at the same time and location, the consensus panel recognise the logistical challenges of delivering this aspirational recommendation in all centres.

In the case of colonic dysplasia, a trade-off in risks needs to be considered when deciding between having potentially life-altering surgery or continuing surveillance with the ongoing risk of developing a metachronous cancer. Patient-centred relationships with trusted clinicians engaged in shared decision-making are associated positively with increased patient comprehension of the risks and benefits of treatments and increased satisfaction with the patient's role in decision-making.<sup>52,57</sup> IBD patients value preference-based shared decision-making highly,<sup>58</sup> but it does not appear to be routinely practised.<sup>59</sup> To facilitate shared decision-making, a multi-step process should occur [Figure 1].<sup>14,15,60–62</sup> The risks and attributes that IBD patients most highly value when making decisions about their treatment include the impact on symptoms including pain, bowel urgency, and fatigue, the impact on longer-term health-related QOL including their emotional status, diet, ability to complete daily tasks, and their sexual and social life and interpersonal interaction, as well as the risks of cancer, serious infections, and anaesthetic-related complications.<sup>63,64</sup>

Procedural and cancer risks should be communicated effectively to maximise patient comprehension [Supplementary Table 5]. The majority of the DECIDE patient stakeholders indicated that personalised cancer risk communication would make them feel better informed and more confident in their decision-making [Supplementary Appendix 2]. In order to support more individualised cancer risk communication, a risk prediction tool which displays cancer risk in a Paling chart format for UC patients with LGD has been developed and externally validated [www.uc-care.uk].<sup>25</sup>

Valid informed consent requires that all alternative treatment options are discussed, including doing nothing.<sup>65,66</sup> IBD patients have expressed a desire to be given more information about alternative treatment options earlier in their disease course, to make more informed decisions.<sup>52,59</sup> Endoscopic treatment options for dysplasia include polypectomy and/or more intensive surveillance monitoring. Proctocolectomy [with either a permanent ileostomy or an ileoanal pouch anastomosis] is advocated as the surgical option of choice for higher cancer risk colitis patients, but the alternative surgical options of less extensive rectum-preserving colectomy [subtotal colectomy with ileorectal anastomosis or segmental

colectomy] may be discussed with selected patients.<sup>12,67,68</sup> Discussions regarding the preferred choice of management will also be influenced by local expertise and availability. Not all centres have access to ESD or pouch surgery and some centres may be able to provide continent ileostomy as an alternative surgical option. A decision grid summarising the advantages and disadvantages of each management option has been constructed to aid more comprehensive communication with patients during the consultation [Supplementary Appendix 4].

### 3.2.1. Endoscopic management of higher-risk colitis-associated dysplasia

Colitis patients often prefer to continue surveillance and endoscopic management after a high-risk dysplasia diagnosis, especially those in clinical remission.<sup>5–8</sup> The DECIDE patient stakeholders wanted to avoid or delay colectomy surgery due to concerns about its impact on their quality of life and mental wellbeing and due to other familial and societal pressures [Supplementary Appendix 2]. Patients are reassured by the protection that colon surveillance offers.<sup>69</sup> IBD surveillance patients appear to have a good quality of life and comparable anxiety and coping ability scores to lower cancer-risk patients not yet on a surveillance programme.<sup>8,70,71</sup> Although patients continuing surveillance may be able to avoid surgery in the short term, they should be counselled on the risk of developing active inflammation, which may need medical therapies and/or surgery in the long term, and the associated greater future cancer risk.

IBD patients may overestimate the benefit that colonoscopic surveillance carries in reducing their cancer risk, and these expectations should be managed appropriately.<sup>5,6</sup> Post-colonoscopy colorectal cancer rates are significantly elevated at 35.5% in IBD patients.<sup>17</sup> These are considered to occur where: [i] dysplastic lesions may have been missed, often due to inadequate bowel preparation, active inflammation, or post-inflammatory mucosal changes; or [ii] where the colon appears to be primed for a biologically more aggressive neoplastic evolution process indicated by the presence of active inflammation or previous dysplasia; or [iii] the recommended surveillance interval or surgical management has not been adhered to.<sup>72–76</sup> The quality of surveillance undertaken, as dictated by factors such as the procedural frequency, bowel preparation tolerance, quality of the mucosal visualisation, equipment availability, and the expertise of the endoscopist, all need to be borne in mind when counselling patients about their long-term cancer risk and potential for missed

1. Explain that a choice needs to be made between several management options, each with its own risks and benefits.
2. Make it clear that the patient has a central role in the discussion and that their preferences are essential to make a decision.
3. Relay information regarding all the management options to the patient, acknowledging where there is uncertainty.
4. Elicit the patient's values and goals with particular emphasis on what is important to them to maintain their long-term quality of life, e.g. bowel function, diet, work, interpersonal relationships, family life, fecundity.
5. Consider these values and what the patient is willing to trade-off when comparing the risks and benefits of each management option.
6. Encourage patient engagement by limiting medical terminology, allowing time for deliberation and further questions, before agreeing on a decision based on the patient's informed preferences.

Figure 1. Multi-step process to use when making shared decisions with a patient

neoplastic lesions despite surveillance. Continued surveillance after a dysplasia diagnosis should be performed by an endoscopist deemed to have appropriate experience in IBD surveillance and with access to high-definition imaging and chromoendoscopy [dye and/or virtual].<sup>33</sup> Patients should be counselled about the consequences of developing a colitis-associated colorectal cancer despite surveillance, which is associated with a poorer prognosis compared with sporadic cancers and with the possibility of it being incurable at diagnosis.<sup>2,77</sup> Compared with a proctocolectomy performed for LGD, a cancer diagnosis may require more extensive surgical pelvic dissection and chemotherapy and/or radiotherapy, with a greater consequence on quality of life, sexual function, and fecundity.

The risks of a diagnostic surveillance colonoscopy are low, but the risks of peri-procedural complications with advanced polypectomy techniques, particularly if there are large, multiple, or recurrent lesions, should be explained where indicated.<sup>26,27,78</sup> In a meta-analysis<sup>79</sup> of 11 studies with 506 IBD patients [610 dysplastic lesions; mean diameter 23 mm] who underwent EMR, ESD, or hybrid ESD, pooled perforation rates were 0%, 3.8%, and 4.1%, respectively, and pooled bleeding rates were 1.4%, 2.3%, and 9.5%, respectively. Reassuringly, however, most of these complications can be managed endoscopically without the need for surgical intervention. Patients may need to travel to a regional centre if they have a complex dysplastic lesion requiring EMR or ESD. The patient's preferences should be obtained prior to the referral, as they may not wish to travel far from home and if there is a risk of needing admission post-procedure. Despite the practical difficulties, the IBD patient stakeholders informing these consensus statements welcomed a referral for a second opinion in a regional centre if it could mean safely avoiding colectomy [Supplementary Appendix 2].

### 3.2.2. Surgical management of higher-risk colitis-associated dysplasia

The recommended surgical option for colitis-associated dysplasia is proctocolectomy.<sup>12,67,68,80–82</sup> Panproctocolectomy with excision of all anorectal tissue and perineal closure and formation of a permanent ileostomy may be preferred over restorative proctocolectomy with ileoanal pouch anastomosis [IPAA], as it eradicates UC and long-term colorectal cancer risk.<sup>12</sup> Given the segmental nature of Crohn's colitis and the risk of recurrence throughout the gastrointestinal tract, less extensive [including segmental] colectomy, may be considered in selected cases.<sup>68,81,82</sup> A less extensive colectomy with anastomosis is associated with lower complication rates compared with proctocolectomy.<sup>83–86</sup> Due to its lower associated morbidity, subtotal colectomy with IRA may also be considered in carefully selected cases of older, more comorbid UC patients with a higher peri-operative risk.<sup>12,67,80</sup> Unlike with proctocolectomy, rectum-preserving colectomy surgery is not associated with sexual dysfunction<sup>87,88</sup> or reduced fecundity,<sup>89</sup> and therefore selected younger UC patients may want to consider a subtotal colectomy and IRA.<sup>12,67,80</sup> Patients being considered for an IRA should meet the following criteria: the neoplasia is located in a proximal colonic segment, their rectal disease is quiescent or mild, there is reasonable rectal and anal sphincter function, there is a low risk of dysplasia in the retained rectum, and they are willing to comply with postoperative surveillance of the rectal remnant.<sup>12,67,80</sup> Although less extensive colectomy is inferior to

proctocolectomy in terms of long-term metachronous neoplasia risk, several of the stoma- and pouch-averse DECIDE patient stakeholders expressed being more accepting of surgery if less extensive colonic resection and a primary anastomosis was discussed [Supplementary Appendix 2]. It is essential that patients considering less extensive colectomy are willing to adhere to regular endoscopic surveillance of the remaining colorectum and are well informed about the risks of needing further medical or surgical therapy if they were to develop active inflammatory disease or cancer.

Restorative proctocolectomy with IPAA is normally performed in two to three staged operations and is only offered by specific institutions. The longer recovery time and travel distance from home to the hospital for multistage operations, re-admissions for complications, and outpatient follow-up may have personal financial as well as functional implications that need to be considered when decision-making. The UK Surgical Workload Outcomes Audit Database [SWORD]<sup>90</sup> identified national average 30-day re-admission and re-operation rates after pouch surgery to be 27.4% and 6%, respectively. Panproctocolectomy and end ileostomy formation are normally performed in one operation, which may make it a more attractive option for patients who desire less elective hospital admissions and a shorter overall recovery time. A continent ileostomy [eg, Kock pouch] may be considered in some selected cases. A systematic review of continent ileostomy outcomes indicates good quality of life outcomes, but reoperation rates due to complications are high [20.8–65%.]<sup>91</sup>

The risks associated with proctocolectomy or less extensive colectomy are influenced by a number of factors which are specific to the patient [age, comorbidities, and functional performance status], operating surgeon, and institution. Surgeons are expected to have detailed discussions regarding these risks when consenting patients for surgery. This level of detail is outside the remit of these consensus standards; however, the DECIDE steering group agreed that, to have transparent discussions when counselling IBD dysplasia patients about management, it would be helpful for non-surgical IBD specialists to have some evidence-based and consensus-agreed general surgical risk information as presented here.

#### 3.2.2.1. Postoperative complications

Mortality is low [ $<1\%$  risk] after colectomy surgery, but increases with factors such as increased patient comorbidities.<sup>92–95</sup> General shorter-term morbidity related to colectomy surgery may include wound healing delays, anastomotic leak, infections, venous thrombosis, bleeding, and small bowel obstruction or ileus, and may have longer-term ramifications [Table 4]. Reported short-term complication rates vary in the literature, due to the inclusion of historical data from retrospective cohort studies with differing proportions of emergency and tertiary-centre cases. Clinicians are therefore encouraged to seek up-to-date institutional data when quoting risks. Overall, shorter-term complications of surgery may affect about one-third of patients.<sup>93,96,97</sup> Most can be treated conservatively, but 8.4–11.3% may require re-operation.<sup>94,98</sup> Laparoscopic approach appears to be associated with the lowest mortality and morbidity rates compared with open approaches.<sup>95,99,100</sup>

Potential longer-term complications associated with end ileostomy formation include skin irritation, retraction, stenosis, prolapse, hernia, and high output. There is a 20–30% risk of requiring a re-do operation due to stoma complications over

**Table 4.** Reported postoperative complication rates associated with proctocolectomy

Postoperative complication	Reported prevalence
Mortality	<ul style="list-style-type: none"> <li>• Low [<math>&lt;1\%</math>] risk but increases with factors such as increased patient comorbidities<sup>92–95</sup></li> </ul>
Infection	<ul style="list-style-type: none"> <li>• Meta-analysis<sup>130</sup>: <b>pooled wound infection</b> rates in UC patients who had an elective panproctocolectomy with ileostomy formation [<math>n = 11\ 686</math>] was 6.8–14%</li> <li>• Systematic review<sup>93</sup>: <b>pooled rate of any infection</b> after colectomy reported to be 22% [<math>n = 207/938</math> UC patients; 8 studies]</li> <li>• <b>Surgical site infections</b> reported to occur in 18–23%<sup>95,98,189</sup></li> <li>• <b>Pneumonia and sepsis</b> reported in 8–10%<sup>95,98</sup></li> <li>• <b>Pelvic infections</b> reported to occur in 5–25% of patients who have had a restorative proctocolectomy with IPAA patients and is the commonest cause of pouch failure<sup>90,105,106,130,132,140,190,191</sup></li> </ul>
Anastomotic leak	<ul style="list-style-type: none"> <li>• Data from the largest cohort studies report anastomotic leak rates of 3–7% and pelvic sepsis rates of 9–12%, with the highest rates occurring in patients with Crohn's disease<sup>90,132,140</sup></li> <li>• Studies of IBD patients who have had subtotal colectomy with IRA have shown anastomotic leak rates of 3–8%.<sup>83,148,192</sup></li> </ul>
Small bowel obstruction and ileus	<ul style="list-style-type: none"> <li>• Common complication after proctocolectomy with either end ileostomy or pouch formation, affecting around 5% in the early postoperative period and 10–20% in the longer term<sup>90,93,105,130,132,140,193,194</sup></li> <li>• Most cases are managed conservatively but 25% may require operation<sup>142</sup></li> </ul>
Systemic venous thrombosis	<ul style="list-style-type: none"> <li>• Reported to occur in 3–7% of cases,<sup>130,142,195</sup> with less occurring in elective than emergency cases<sup>195</sup></li> </ul>
Ileostomy complications	<ul style="list-style-type: none"> <li>• Include skin irritation, retraction, stenosis, prolapse, hernia, and high output</li> <li>• Permanent end ileostomy: 20–30% risk of requiring a re-do operation due to stoma complications over 10 years<sup>101,102</sup></li> <li>• Temporary ileostomy and subsequent reversal with IPAA: 10–20% risk of complications<sup>103,104</sup></li> <li>• Japanese single-centre study reported cumulative probability of stoma revision surgery to be higher in Crohn's [29.6% at 10 years] compared with UC [14.5% at 10 years] patients due to disease recurrence and fistula formation<sup>101</sup></li> </ul>
Sexual dysfunction and infertility	<ul style="list-style-type: none"> <li>• Increased if proctectomy performed [see Section 2.2. for further detail]</li> <li>• Meta-analyses<sup>105,106</sup> reported sexual dysfunction rates of 3.0–3.6% after restorative proctocolectomy and IPAA [<math>n &gt; 5000</math>]</li> </ul>

UC, ulcerative colitis; IPAA, ileoanal pouch anastomosis; IBD, inflammatory bowel disease; IRA, ileorectal anastomosis..

10 years,<sup>101,102</sup> with the highest risk in Crohn's patients.<sup>101</sup> Most centres will advocate the formation of a diverting loop ileostomy with IPAA. Although this ileostomy is usually temporary, this and the subsequent reversal may still be associated with significant morbidity [affecting 10–20%].<sup>103,104</sup>

### 3.2.2.2. Sexual function and fecundity

The additional pelvic dissection required for proctectomy and pouch formation may result in nerve damage, anatomical changes, and formation of scarring and adhesions that lead to sexual dysfunction, reduced fecundity [ie, the probability of conceiving per month or year of unprotected sexual intercourse], and increased infertility [ie, inability to conceive after 1 year of unprotected sexual intercourse]. When conveying these risks to patients making decisions about surgical management of dysplasia, patient factors [eg, previous pelvic surgery] and operating surgeon and institutional data should be taken into consideration. They should also be made aware that surgically untreated disease may also be associated with decreased sexual function and fecundity, if medically refractory active inflammation or a cancer were then to develop, requiring more extensive resection planes.

#### [i] Overall sexual dysfunction

Heterogeneity in the definition of sexual dysfunction, lack of comparison with pre-operative baseline and the inclusion of both open and laparoscopic approaches make it difficult to accurately quantify this risk from the literature available. Meta-analyses<sup>105,106</sup> of outcomes after restorative

proctocolectomy and IPAA have reported sexual dysfunction rates of 3.0–3.6% [ $n > 5000$ ]. However, a systematic review<sup>107</sup> noted that the majority of more recent observational studies [ $n = 6$ ] published between 2004 and 2014 showed comparable postoperative sexual function scores in proctocolectomy and control groups. Sexual dysfunction may not be long term, as demonstrated by a Dutch prospective case-control study [ $n = 83$ ] where sexual activity returned to comparable pre-operative levels by 8.5 years of follow-up after proctocolectomy.<sup>87</sup> No differences in sexual dysfunction have been found when comparing open and laparoscopic-assisted IPAA for UC.<sup>108–110</sup>

#### [ii] Sexual dysfunction in men

In the largest case series of male UC patients who had a restorative proctocolectomy and IPAA at the Mayo clinic [ $n = 762$ ], retrograde or no ejaculation was reported by 3% after 10 years and sexual dysfunction was reported in 1% at 1 year and in 2% at 12 years.<sup>111</sup> Prospective cohort studies using validated sexual function scores have demonstrated improved or no significant change pre- and post-proctocolectomy in IBD, although this may be a result of the removal of diseased colon as reflected by corresponding increases in general health-related QOL scores.<sup>112–115</sup> Post-proctectomy erectile dysfunction more likely occurs in older men [ $>50$  years old] rather than younger men<sup>113,115,116</sup> and is often medically treatable.<sup>117</sup> Sildenafil completely

reversed or satisfactorily improved erectile dysfunction in 79% of post-proctectomy patients [ $n = 32$ ] in a randomised controlled trial.<sup>117</sup>

[iii] **Sexual dysfunction in women**

Sexual dysfunction is more difficult to define in women. Older studies have tended to focus on self-reporting of dyspareunia as a marker of sexual dysfunction, which has been shown to increase post-proctectomy and post-IPAA and affect about 8–25% of women.<sup>87,111,118</sup> However, the same studies have shown an increase in overall sexual satisfaction<sup>118</sup> and a return to pre-operative baseline levels of sexual activity at 1 year post-proctocolectomy.<sup>87</sup> More recent studies have incorporated several domains including desire, arousal, lubrication, orgasm, satisfaction, and pain into a validated Female Sexual Function Index [FSFI]. Prospective cohort studies using the FSFI have shown high levels of sexual dysfunction pre- and postoperatively, but they tend to improve<sup>112,114</sup> or are unchanged<sup>113,119</sup> at 6–12 months follow-up after a proctocolectomy. Again, it is not clear whether the improvements are due to removal of the diseased colorectum. There has been contradictory evidence on whether pouch dysfunction contributes to sexual dysfunction in women.<sup>120,121</sup>

[iv] **Fecundity and fertility**

Meta-analyses have demonstrated 2–5-fold increased 1-year infertility rates in UC female patients after proctocolectomy, but include low-quality observational studies of mainly open surgery with significant between-study heterogeneity.<sup>118,122–125</sup> In a meta-analysis<sup>123</sup> of six studies with patients who were attempting pregnancy, weighted average infertility rates increased from 20% pre-operatively to 63% postoperatively [ $n = 457$ ]. Increased use of fertility treatments from 16% pre-IPAA to 51% after IPAA was reported in a systematic review.<sup>118</sup> The reduced fecundity is believed to be related to scarring and adhesional occlusion of the fallopian tubes from the pelvic dissection. This is supported by the much higher pregnancy success rate reported after *in vitro* fertilisation and implantation of the embryo directly into the uterus in pouch patients [30%] compared with the reference population [1.3%].<sup>126</sup> Small observational studies have suggested better fecundity rates in women after laparoscopic restorative proctocolectomy and IPAA.<sup>127–129</sup>

3.2.2.3. *Bowel function and risk of active disease recurrence postoperatively*

[i] **Panproctocolectomy and end ileostomy formation**

UC patients who opt for a panproctocolectomy with complete excision of the rectal mucosa and perineal closure eliminate their risk of future active colitis. Crohn's patients, however, remain at risk of recurrence at non-colorectal sites. The pooled rate of clinical recurrence in the small bowel was 28% overall [95% CI 21.7–35.3;  $n = 260/1004$ ] and 11.5% [95% CI 7.7–16.8] if there was no prior history of ileal disease, in

a meta-analysis of outcomes after panproctocolectomy for Crohn's.<sup>102</sup>

[i] **Restorative proctocolectomy and IPAA**

- a. **Pouch function.** The pouch is meant to act as a reservoir for stool but is inferior to the rectum in its function, and so patients should expect normal pouch function to include three to eight evacuations in 24 h, including one to two times overnight.<sup>105,130</sup> Pouch function appears to improve within the first 5 years after surgery with a slight decline over the decades.<sup>131</sup> Pouch dysfunction can occur due to incomplete emptying, urgency, incontinence, and pouchitis, which can lead to pouch failure. Pooled incidences of mild and severe daytime incontinence have been reported at 14–17% and 3.7–6.1%, respectively, in meta-analyses.<sup>105,106</sup> On average, half may require medication [eg, stool bulking agents, loperamide] to alter their bowel transit.<sup>131</sup> In a Cleveland clinic cohort [ $n = 1312$ ], a third experienced urgency, 21% wore pads during the day, 26% wore pads at night, but 81% had never or rarely experienced incontinence at 10 years post-IPAA.<sup>132</sup> A systematic review found similar long-term functional outcomes in Crohn's patients as has been reported for patients with UC.<sup>133</sup>
- b. **Pouchitis** causes symptoms of stool frequency, urgency, and abdominal pain which may require biologic therapy or surgical pouch excision for refractory cases.<sup>134</sup> A prospective Mayo clinic study found a 10-year rate of acute pouchitis of 48% for UC and 59% for Crohn's patients, and an overall cumulative probability of 81% at 30 years [ $n = 1875$ ].<sup>131</sup> Pooled rates of chronic pouchitis in updated meta-analyses of UC IPAA patients are reported as 13%–23%.<sup>130,135</sup> PSC patients are at a higher risk.<sup>136</sup>
- c. **Cuffitis** occurs when the cuff of residual rectal columnar mucosa to which the ileal pouch is anastomosed develops inflammation and rectal bleeding and urgency.<sup>134</sup> In a single-centre cohort study, cuffitis was seen in 30% [ $n = 119/386$ ] of IBD IPAA patients who had pouchoscopy over a median of 4 years.<sup>137</sup> Reassuringly most respond to topical 5-aminosalicylate or steroid suppositories.<sup>138</sup>
- d. **Pouch failure** is defined as the formation of a permanent ileostomy with or without excision of the pouch, and usually occurs due to poor pouch function in addition to septic complications. However, this definition can also include patients who have decided not to reverse their ileostomy because their quality of life with a stoma was better than expected. Ten-year pouch failure rates have been reported at 5–10% in UC, and up to 37% in Crohn's patients with peri-anal fistulising and septic complications.<sup>90,105,106,130–133,139–141</sup> However, the rate was only 15% in patients with known pre-operative diagnosis of Crohn's compared with postoperative *de novo* Crohn's diagnoses, in a systematic review.<sup>133</sup> Pouch surgery is not contraindicated in selected PSC or Crohn's patients in some

centres,<sup>68</sup> but it is essential that these patients are counselled about the high associated pouch failure rates.

- e. **Strictures at the pouch-anal anastomosis** can cause straining, incomplete evacuation, watery stools, and urgency. It has been reported to occur in 9–20% of IBD patients by 10 years.<sup>105,130–132,139</sup> The majority respond to digital or graduated Hegar's dilatation,<sup>132</sup> but more refractory strictures may require surgical intervention.<sup>142,143</sup>

[iii] **Subtotal colectomy and ileorectal anastomosis [IRA]**

- a. **Normal rectal function** after IRA is altered due to functional changes.<sup>144</sup> Reported median bowel movement frequency is four to six times during the day and none or once at night.<sup>83</sup> Nocturnal seepage/incontinence reportedly affects 0–8% and urgency affects 20–68%.<sup>83</sup> Two single-centre studies found similar HRQOL in UC IPAA and IRA patients, but the IRA group demonstrated less bowel frequency [median 5–6 vs 7] and greater urgency.<sup>88,144</sup>
- b. **Risk of proctitis recurrence** requiring treatment [usually topical 5-aminosalicylates] after IRA has been reported as 9–76%.<sup>83,85,88,145</sup> The variation is likely related to discrepancies in the length of recto-sigmoid left *in situ* and follow-up durations. The cumulative risk of Crohn's recurrence has been reported as 43% at 5 years and 67% at 10 years,<sup>146</sup> or 3-fold higher than proctocolectomy.<sup>84</sup>
- c. **IRA survival** [avoidance of a proctectomy]. Cumulative rates have been reported at 63–76% at 10 years<sup>85,88,145,147,148</sup> and 46–60% at 20 years.<sup>88,147</sup> The main reasons for a completion proctectomy after an IRA are proctitis, poor function, or neoplasia developing in the rectum.

[iv] **Segmental colectomy and primary anastomosis**

Risk of Crohn's colitis recurrence after segmental colectomy, requiring a re-operation, has been reported at 27–31% after approximately 15 years' follow-up in the largest cohort studies.<sup>149,150</sup> A meta-analysis of 11 studies demonstrated no significant difference in surgical Crohn's disease recurrence between those who had subtotal colectomy [ $n = 510$ ] and segmental colectomy [ $n = 500$ ].<sup>84</sup> There are less data on the risk of UC recurrence after segmental colectomy. In a multicentre retrospective cohort study of UC patients with mainly left-sided disease, who had a segmental colectomy performed for reasons other than active colitis [eg, neoplasia or colonic stenosis], 49.3% [ $n = 34/69$ ] developed clinical UC recurrence after follow-up of a median of 3.3 years, and 20.3% required re-operation after a median delay of 19 months due to refractory colitis.<sup>86</sup>

3.2.3.4. *Health-related quality of life [HRQOL]*

Overall HRQOL has been found to be high and comparable in longer-term follow-up studies of panproctocolectomy with end ileostomy versus restorative proctocolectomy with IPAA.<sup>151,152</sup> Some HRQOL domain/item-specific differences have been observed in end ileostomy patients, including lower body image satisfaction,<sup>151,153,154</sup> less dietary restriction<sup>154</sup> and conflicting results for the impact on social/work functioning.<sup>153,155,156</sup> However, interpretation is limited by

small sample sizes, limited follow-up, heterogeneity in the tools used to measure HRQOL, and a more comorbid population opting for end ileostomy formation over a pouch. Longer-term single centre follow-up studies have suggested good longitudinal HRQOL after pouch surgery.<sup>131,132</sup> After 10 years, on average only 12% reported any social, work, or sexual restrictions and 24% reported any dietary restrictions, in the Cleveland clinic study, with no significant differences between UC [ $n = 1312$ ], Crohn's, and familial adenomatous polyposis patients.<sup>132</sup> After 30 years post-pouch surgery at the Mayo clinic, minor restrictions in their diet, travel, and recreation were reported by 46%, 34%, and 31% of IBD patients, respectively, but 82% did not think that their work was affected and 95% did not report any severe restrictions on their recreational activities.<sup>131</sup> It should be borne in mind when counselling patients, that the high postoperative HRQOLs observed in these studies may have been driven by removal of the inflamed colon, which may not be relevant to a dysplasia cohort in clinical remission.<sup>130,157</sup>

3.2.3.5. *Risk of post-operative cancer*

[i] **Pouch cancers**

Most pouch cancer arise from retained rectal cuff. The overall risk of a pouch adenocarcinoma is low [ $<1.5\%$  at 10 years],<sup>158–160</sup> but the risk is substantially elevated [9–15-fold] in colitis patients with prior colonic neoplasia.<sup>158,161–163</sup> In meta-analyses including around 5000 pouch patients, pouch cancers were more likely in those with a previous history of colorectal cancer [OR 15.0; 95% CI 6.6–34.5],<sup>158</sup> dysplasia [OR 4.4; 95% CI 1.9–10.1],<sup>158</sup> or any colonic neoplasia [OR 8.8; 95% CI, 4.6–16.8].<sup>161</sup> It is therefore recommended that patients who have IPAA surgery for dysplasia, have annual endoscopic pouch surveillance postoperatively.<sup>9–11</sup> No cancers developed over a median of 8.6 years in a prospective Dutch single-centre study of IBD pouch patients [ $n = 44$ ] who had neoplasia detected in their colectomy specimens followed by chromoendoscopy pouch surveillance.<sup>163</sup>

[ii] **Rectal cancer after colectomy and IRA**

The overall pooled prevalence for post-IRA UC patients was 1.6% [95% CI 0.8–2.6%], in a meta-analysis of studies published after 1990.<sup>158</sup> The absolute cumulative risk has been reported as 0–0.3% at 5 years, 0–2% at 10 years, and 2–14% at 20-years' follow-up.<sup>85,88,159</sup> However, the risk of rectal cancer was 15-fold higher than in the general population [standardised incidence ratio 15.3; 95% CI 3.8–61.3] in a Swedish, population-based, cohort study of post-IRA UC patients who had a pre-operative diagnosis of dysplasia [ $n = 1112$ ].<sup>159</sup> The cumulative incidence of rectal cancer was 25% after 10 years' follow-up [95% CI 0.4–57.4] in a French multicentre study of post-IRA UC patients who also had pre-operative dysplasia [ $n = 343$ ].<sup>164</sup> Data on the risk of post-IRA rectal cancer in Crohn's patients are limited by much smaller studies which have included pre-operative cancer diagnoses. In a case series of Crohn's patients who had a subtotal or segmental colectomy for pre-operative dysplasia and were followed up for a median 6 years, one patient [9%;  $n = 1/11$ ] who had

not complied with surveillance developed a rectal cancer.<sup>165</sup> In another case series of Crohn's patients who had an IRA for pre-operative cancer diagnoses, 35% [ $n = 6/17$ ] developed metachronous rectal cancer within a median follow-up of 6.8 years, despite most [85%] having annual surveillance.<sup>166</sup> Patients should be advised that annual endoscopic surveillance of the rectum will still be required after a colectomy and IRA for dysplasia. If a rectal cancer were to develop and be managed with a completion proctectomy and radiotherapy, subsequent IPAA is associated with increased pouch failure rates.<sup>167-169</sup>

#### [iii] Colorectal cancer after segmental colectomy

Reported rates of metachronous neoplasia if segmental colectomy has been performed for cancer, have varied from 0% to 40% over a 7-year surveillance follow-up period, with the highest incidences occurring in patients who pre-operatively had cancer rather than dysplasia.<sup>86,166,170-172</sup> Recent studies reflecting modern surveillance and high-definition endoscopic imaging practices suggest that the true synchronous rates are much lower than previously reported.<sup>4,173</sup> In a small Chicago case series of IBD patients [ $n = 17$ ] with confirmed distal colonic neoplasia, who underwent segmental or subtotal colectomy with IRA, no patient developed advanced neoplasia in the remaining colon over a median 17 months' follow-up with two high-definition colonoscopies.<sup>171</sup>

## 4. Supporting Decision-making Post-consultation

Expert guidance on obtaining consent and shared decision-making recommend that sufficient time and additional resources be provided to the patient while they deliberate and consider their values and wishes, including facilitating a second opinion if sought by the patient.<sup>14,15,60,66</sup> A total of 80% of the DECIDE patient stakeholders greatly valued being given time after their initial consultations, to independently investigate their options by reading literature and speaking to specialist nurses or other patients [Supplementary Appendix 2]. The gains in knowledge and autonomy resulting from this process reduced their anxiety and hesitancy in making a decision.

Visual decision aids were considered to be important decision-making facilitators by the DECIDE patient stakeholders and the independent decision-making expert, in view of the potentially overwhelming amount of technical details about the management options and the risk information that needs to be conveyed. Paper and web-based visual aids have been shown to facilitate confident decision-making in IBD patients choosing between surgical and/or medical options for symptomatic IBD.<sup>174-176</sup> None are specifically relevant for dysplasia with asymptomatic colitis, and so we have developed a new patient-facing decision aid to help support decision-making, including signposting to patient support groups or charities [Supplementary Appendix 5]. The majority [80%] of the DECIDE patient stakeholders and other qualitative research indicate that patients strongly value the opportunity to speak to other patients about their lived experiences with a pouch or stoma and to answer the questions that health professionals cannot.<sup>21,53,56,64</sup> Nurse specialists in

IBD and/or pouch and stoma care play an important role in counselling by providing patient-centred information, emotional and practical support, managing expectations, and providing reassurance to patients<sup>64,177,178</sup> [Supplementary Appendix 2]. An opportunity to meet with a specialist nurse should be offered after the initial medical-surgical consultation.

Often patients wish to consolidate their views and have an opportunity to ask further questions with a known clinician at a second consultation, before they agree on an informed preference-based management option.<sup>14,15,60</sup> Several of the DECIDE patient stakeholders revealed that the emotional impact of being given a pre-cancerous or high cancer-risk diagnosis hindered information retention at their initial consultation with the gastroenterologist or surgeon [Supplementary Appendix 2]. A lack of continuity of clinician care and limitations on the consultation appointment time were cited as barriers to patient engagement in shared decision-making and satisfaction with their care. However, if a patient defers the decision for a significant length of time, eg, more than 6 months, a repeat endoscopy to ensure no advanced neoplasia progression should be offered.

## 5. Discussion

An international multidisciplinary expert Delphi panel has defined consensus-derived statement recommendations to optimise and standardise the quality of information given to IBD patients with dysplasia, about their alternative management options using a shared decision-making approach. Strong consensus [90% or higher agreement] on the DECIDE statements among the Delphi panel was achieved quickly in only two voting rounds. Most of the statements are supported only by low- or very low-quality evidence, due to a lack of randomised, interventional study data and reliance on small population, retrospective, and heterogeneous study data. Data on long-term cancer risk after an invisible dysplasia diagnosis or endoscopic submucosal dissection of large, non-polypoid lesions are limited. The literature review on colectomy outcomes was limited by the lack of studies that include sub-analyses of IBD patients with dysplasia in clinical remission. This makes comparison of functional, quality of life and metachronous cancer risk outcomes between surgical options for dysplasia, rather than medical refractory disease, challenging. Although some patients may desire less extensive colectomy and avoidance of stoma or pouch formation, no studies have evaluated the impact of high-quality modern pouch or colorectal remnant endoscopic surveillance on the cumulative risk of metachronous neoplasia, making future cancer risk counselling difficult in these patients.

The low quality of evidence validates the use of an anonymous Delphi voting method to identify best standardised practice among a group of multicentre, international specialists. Consultation with a decision-making expert and patient stakeholders has encouraged a patient-centred approach in the development of these consensus statements. The statements support a multidisciplinary team approach to managing dysplasia and counselling patients, and reiterate the need for high-quality surveillance and expert, advanced endoscopist input to ensure colitis-associated visible dysplasia is optimally managed. They identify the risk factors that put an IBD patient with dysplasia at higher risk of developing cancer, and should prompt careful counselling about the benefit of

prophylactic colectomy over continued surveillance, ideally conducted in a joint physician-surgical clinic and using the principles of shared decision-making. They highlight the benefits of permitting patients time for deliberation and access to specialist nurses and trained patient advocates, who can provide balanced information on pouch or stoma care, to facilitate confident decision-making.

Rapid attainment of consensus among the Delphi panel implies that the statements reflect standardised best practice among a large group of 38 multidisciplinary international team members [31 Delphi panel members; seven Steering Group members]. However, this may reflect homogeneous clinical practices within the panel, and the low quality of data associated with most of the statements may have encouraged a more experienced-based rather than an evidence-based approach to the content of the consensus statements. Most of the panel members were from the UK and Europe, and there was only one participant from North America and two from the Australasian region. Although relatively equal numbers of gastroenterologists and colorectal surgeons were included, only two of the panel members were specialist nurses, and most [84%;  $n = 26/31$ ] of the panel members were from a tertiary academic centre. The use of a snowball sampling recruitment method may have encouraged participation of health professionals with similar clinical practices, but the use of this recruitment method was minimal, and most of the Delphi panel members were recruited prospectively in response to the advertisement distributed with a clinician survey.<sup>3</sup>

Decision aids have been informed by the DECIDE consensus statement building process, which can be used by health professionals and patients to support the counselling and decision-making process [Supplementary Appendices 4 and 5]. However, in future work these would need to be prospectively tested in real-life clinical settings, to evaluate their utility in improving the quality of information that is provided to IBD patients with dysplasia and confidence in the final shared management decision made.

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## Conflict of Interest

None declared by all the authors with respect to the content of this paper.

## Author Contributions

MK, AW, STG, and ALH contributed to the concept and design of the study. MK and AW contributed to the acquisition, analysis, and interpretation of the data and to drafting and revising the article. MK, AW, STG, JW, ODF, PJT, and LA formed the steering group that drafted the initial consensus statements. All authors contributed to the acquisition and interpretation of the data, revising the article critically for important intellectual content, and approving the final version of the article to be published. All authors agree to be accountable for all aspects of the work, and MK holds overall responsibility for the content and integrity of the paper.

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## Supplementary Data

Supplementary data are available at ECCO-JCC online.

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