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## CONSENSUS/GUIDELINES

# N-ECCO Consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis

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## 1. Introduction to N-ECCO Statements

N-ECCO (Nurses-European Crohn's & Colitis Organisation) has been an active member of ECCO since 2007, with the purpose of providing nurse education and the opportunity for nurses to network internationally. N-ECCO aims through its activity to improve nurses' knowledge of Inflammatory Bowel Disease (IBD), share best practice and thus improve the quality of care accessed across Europe by patients with IBD.

It has long been acknowledged in N-ECCO that nurses across Europe perform and provide varying roles in caring for

patients with IBD, given the country-specific variances in role, title, salary and level of training.

### 1.1. Aims

The intentions of the N-ECCO Consensus statements are to identify the positioning of nurses (adult and paediatric) in the care of patients with IBD and to provide a consensus on the ideal standard of minimum care that patients with IBD might expect, irrespective of the level of nurse training, title or country. The 'ideal' standard of nursing care was deemed an accurate measure and appropriate by the group in order to provide a standard for all nurses working with people with IBD.

### 1.2. Methods

The N-ECCO Committee agreed the need for the consensus statements on the nurses' role in June 2011. Following the Standard Operating Procedure (SOP) of ECCO ([www.ecco-ibd.eu/](http://www.ecco-ibd.eu/)) a proposal for guidelines, along with draft contents for the statements, was submitted to the Governing Board. This was approved in November 2011, with a recommendation to conduct a survey to gain a clear understanding of the current situation of nurses within Europe in caring for patients with IBD. The survey was developed and refined

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within the N-ECCO committee in time for N-ECCO February 2012, when all attending nurse delegates were asked to complete it. Results of this survey will be published separately.

There was an official call from the ECCO Office for nursing participants to be involved in the N-ECCO Consensus in March 2012. Fifteen nurses were selected by the N-ECCO Committee, following self-nomination, given that they all had adequate experience of nursing in the field of IBD. In April 2012, nurses were allocated into one of four working groups to reflect adequate country variances, with each group chaired by a N-ECCO Committee member. Between April & June 2012, each Consensus group was given a defined section of work, based on the draft content at that time:

- (1) Fundamental IBD Nursing
- (2) Advanced IBD Nursing
- (3) Nursing care for particular situations (e.g. fatigue, pregnancy, incontinence)
- (4) The Benefit of an IBD Nurse.

Each group performed an electronic literature search using PubMed (1996–2010), MEDLINE (1966–2010) and EMBASE (1980–2010), via the OVID platform. The search was conducted from the inception of the databases to November 2012. The literature review deployed the recommended grades and levels of evidence according to the Oxford Centre for Evidence Based Medicine<sup>1</sup> as per the ECCO SOP. Nursing studies tend to be qualitative, focusing on exploring patient's issues and experiences, so it is important to acknowledge that the Oxford system of grading evidence gives greater weight to empirical evidence and does not rate qualitative research highly. Although there are grading systems specific to qualitative research, these do not form part of ECCO's SOP and were therefore avoided.

In June 2012, a one day meeting took place with all consensus group members present to discuss the evidence and to draft preliminary statements based on the literature. Between June & September 2012, each group finalised their statements and supporting text. This was in turn reviewed at the N-ECCO Committee Meeting in October 2012. A further one day meeting took place in November 2012 to vote on each individual N-ECCO Consensus statement. Each of the 26 Consensus statements were voted upon and, in line with the ECCO SOP, agreed by greater than 80% of the groups' vote. Further to this meeting an editorial board consisting of four group members (M. O'Connor, P. Bager, J. Duncan, J. Gaarenstroom, L. Younge) refined the supporting text for the corresponding author and each of the Consensus statements.

### 1.3. Format

The Consensus statements have been divided into three sections:

- (1) Fundamental Inflammatory Bowel Disease Nursing
- (2) Advanced Inflammatory Bowel Disease Nursing
- (3) The Perspectives of IBD Nursing.

Fundamental IBD Nursing identifies the basic nursing care required to address the needs of patients with IBD. The

Consensus group suggests that these needs can be addressed by nurses working in various settings. The statements within this section also pertain to those working at an advanced level, as the Consensus group acknowledged that fundamental nursing care & skills were developed and refined with experience in advanced nursing practice.

The section on Advanced IBD Nursing refers to those nurses who, with experience, training and/or education, are practicing advanced nursing care. The statements within this section aim to identify the role of the advanced nurse, acknowledging the expertise in care and management of caseloads of patients with IBD, whilst also recognising the limitations relevant to this level of nursing care.

The section on the Perspectives of IBD Nursing acknowledges the value of IBD nurses and identifies that there is scarce evidence available within literature to support the value of IBD nurses in improving patient outcomes.

## 2. Fundamental Inflammatory Bowel Disease (IBD) Nursing

### 2.1. Definition and requirements

#### N-ECCO Statement 2A

Nurses in contact with patients with IBD working in any setting, need to have basic knowledge of the diseases, know the difference between Crohn's disease and ulcerative colitis, and appreciate the importance of establishing timely therapeutic interventions. Awareness of the key diagnostic strategies and of the main medical and surgical options available in the management of IBD is recommended [EL3]

Inflammatory Bowel Disease (IBD) is an umbrella term given to the life-long ('chronic') bowel diseases of which Crohn's disease (CD) and ulcerative colitis (UC) are the predominant forms. Although the causes of IBD are unknown, it is recognised as an immune-mediated disease, possibly precipitated by a mixture of genetic and environmental factors which may include fastidious childhood hygiene, smoking, or drugs (such as anti-inflammatories, the contraceptive pill, or antibiotics).<sup>2–4</sup> IBD commonly presents in adolescence or young adulthood, and follows a currently unpredictable relapsing and remitting course.

UC is confined to the rectum and colon. Originating in the rectum (proctitis), it can extend proximally to the sigmoid and descending colon (left-sided colitis), or the entire colon (pan, or extensive colitis).<sup>5</sup> The inflammation is continuous and limited to the mucosa. Symptoms include rectal bleeding and passage of mucus and faecal urgency leading sometimes to incontinence. The location and severity of disease activity determines the choice of therapy.

CD affects the gastrointestinal (GI) tract anywhere between mouth and anus. It occurs most commonly in the ileocaecal region, followed by the colon. The inflammation is

intermittent, with patches of disease activity (skip lesions) between areas of healthy mucosa. Symptoms vary according to disease location and include abdominal pain, diarrhoea, weight loss, anorexia and fever. Nausea and vomiting can occur if strictures cause intestinal obstruction.<sup>6</sup> Initially starting as an inflammatory process, CD can progress to a stenosing/stricturing or penetrating/fistulising pattern, adding considerably to the burden of the disease. Fistulae, which most commonly affect the perianal area, may also form between bowel and skin ('enterocutaneous'), bowel and bladder ('enterovesical'), or rectum and vagina ('rectovaginal'). Management can be difficult, complex, and frequently requires surgery.<sup>7</sup>

Medical treatments for IBD aim to induce and maintain remission. Surgery will be necessary for approximately 30% of UC patients and up to 70% of CD patients, at least once in their lives.<sup>7,8</sup> Extra-intestinal manifestations (EIMs) affecting joints, skin, eyes and liver may occur.<sup>9</sup> These can either run in parallel with active disease or independently, even persisting in the case of UC following colectomy. Common symptoms of active disease in both conditions include diarrhoea, abdominal pain, anaemia and fatigue.

Patient history and physical examination are fundamental in diagnosing IBD. Appropriate analysis or culture of diarrhoea (with or without blood) can exclude bowel infections and infestations. Endoscopy with biopsy of the colon and terminal ileum may establish and verify diagnosis. Blood chemistry and haematology tests indicate the presence of inflammation, anaemia and malabsorption. Computed tomography (CT) and magnetic resonance imaging (MRI) scans enable evaluation of disease extent, activity and complications.<sup>6,10</sup> Basic knowledge of diagnostic procedures enables all nurses to support patients with their questions and preparation for investigations.

The complex choice of single or combined drug therapy in the medical treatment of IBD is influenced by the location and severity of the disease, treatment availability and local experience, and by individual patient circumstances such as tolerance, side-effects, drug interactions, pregnancy and personal preference. Detailed explanations of recommended medical treatments are available in current ECCO consensus documents.<sup>7,8</sup> Local protocols and guidelines can also be referred to.

Surgical interventions for UC include subtotal colectomy, panproctocolectomy with a permanent ileostomy, or ileo-anal pouch.<sup>8</sup> Such surgery might be considered 'curative' for UC. Surgery for CD may include small bowel resections, subtotal colectomy and ileo-rectal anastomosis, or panproctocolectomy and permanent ileostomy.<sup>7</sup> Colonic resection is sometimes indicated for isolated disease, and surgery may be necessary to treat fistulae and bowel strictures. Surgery can improve quality of life in patients with CD and relieves patients with UC of unremitting inflammation, although EIMs can remain.<sup>9</sup> A consistent patient-reported fear around surgery is the potential need for a stoma.<sup>11-14</sup> However, stoma-forming surgery may have significant benefits for health related quality of life HRQoL.<sup>15</sup>

Timely therapeutic intervention is essential for disease control. It is recommended that nurses with a basic knowledge of IBD consult the Advanced IBD nurse or gastroenterologist where appropriate, according to local referral procedures.

## 2.2. Impact of IBD on patient's lives

### N-ECCO Statement 2B

Nurses caring for patients with IBD need an awareness of the extra-physical impact of the illness, of patients' key concerns, and the effect of IBD on Health Related Quality of Life [EL4]

In addition to symptoms such as diarrhoea and fatigue, IBD commonly causes patients psychological distress.<sup>16</sup> There may be concerns about the uncertain origins and course of the disease, possibly requiring surgery and/or an ostomy bag, achieving full life potential, loss of bowel control, being a burden on others, producing unpleasant odours, and body image.<sup>17,18</sup> Hospital admission may compound worries about personal achievement potential by causing unwelcome enforced absence from work or studies.<sup>18</sup>

Despite being a major concern, IBD-related incontinence is rarely reported or addressed, but incontinence remains both a fear and a risk.<sup>19-21</sup> Recent evidence suggests that up to 74% of people with IBD experience faecal incontinence not necessarily related to flare-up.<sup>22</sup> During hospital admission, difficulties with bowel control are more likely as relapse is probable, and toilet facilities may be shared between several patients, thus limiting availability. Urgency can be severe, with some patients reporting less than 30 s between the call to stool and the need to defaecate.<sup>23</sup> Loss of bowel control causes such concern that some patients with IBD always ensure that they know the location of the nearest toilet.<sup>23,24</sup> The nurse can provide empathetic support and may be in a position to influence speedier/easier access to facilities. Discreet assistance and maintenance of patient dignity in the event of an incontinent episode is essential.

Health related quality of life (HRQoL) is influenced by IBD in both remission and relapse, although perhaps more so in the latter.<sup>25</sup> Psychological wellbeing can be significantly impaired regardless of disease type or status, possibly attributable to sustained psychological distress.<sup>25-29</sup> Psychological intervention or counselling support may be appropriate for patients demonstrating higher levels of concern although the benefits have not been fully demonstrated.<sup>30-33</sup> Even in remission, background persistent disease-related issues such as fatigue, extraintestinal manifestations and sleep difficulties can also affect HRQoL.<sup>26,34,35</sup>

Individuals with IBD often find that their disease impacts on many aspects of daily life, affecting relationships, schooling, socialising and work life. In a large European study undertaken in collaboration with patient associations, 74% of patients with IBD had taken time off work in the last year owing to their IBD and 40% reported that their IBD had prevented an intimate relationship.<sup>36</sup> Furthermore in this study, patients often felt that their HRQoL is not explored or discussed properly with them during healthcare consultations, as 53% reported that they were unable, during a consultation to discuss something important to them.

Contact with other people with similar health problems may benefit many patients.<sup>37</sup> Sharing experience with others who 'know' what it is like to live with a condition 24 h a day,

365 days a year, can provide important social, emotional and psychological support.<sup>38</sup> Nurses can provide contact details for country-appropriate patient associations, support groups, or patient-related charities. These fulfil an important role in providing specific, accurate and empathetic support for those dealing with a new diagnosis or with major developments of established disease.

### 2.3. Patient advocacy

#### N-ECCO Statement 2C

Nursing involves advocacy for all patients and is of the utmost importance to patients with IBD due to the complex, uncertain and chronic nature of the condition. Advocacy for IBD patients includes identifying their needs and ensuring appropriate access to specialist care [EL4]

An advocate promotes and supports the interests of another.<sup>39</sup> Traditionally rooted in law, advocacy is universally considered a moral obligation in nursing practice, particularly when the patient's ability to make decisions, and to defend or protect themselves physically and emotionally, may be impaired due to illness.<sup>40–42</sup> There is no literature focussing specifically on the nurse's role in advocating for patients with IBD. However examples of advocacy in practice include respecting patients' rights, representing, speaking up for the patient's point of view, protecting dignity and privacy, and defending them from interventions that might cause distress.<sup>43</sup> Many of the interventions for IBD may cause distress, but are necessary, and advocacy in such situations is focussed on enabling the patient to access care which keeps distress to a minimum. Advocacy requires the nurse to understand the needs and preferences of the individual patients with IBD, and to exercise moral and professional obligations to assist the patient in meeting those needs. For non-specialist nurses, this may include ensuring urgent and timely referral to Advanced IBD nurses, gastroenterologists or stoma nurses with whom the patient is already in contact, or assisting patients in voicing their concerns to the team.

### 2.4. Communicating with the patient with IBD

#### N-ECCO Statement 2D

Communication is a two way process. Nurses need to develop an empathetic and active listening role, and be able to provide essential IBD-related information and holistic support [EL4]

Communication is a vital aspect of the nursing role, with verbal and non-verbal skills playing an important part in meeting the needs of the patient. IBD impacts significantly on patients' lives and presents them with many uncertainties. The support, advice, compassion, caring and empathy they receive from IBD nurses is considered highly important to their care.<sup>44</sup>

In any chronic illness where the individual will have an ongoing relationship with health care professionals,

communication is an important factor in building rapport and trust.<sup>45</sup> Establishing and maintaining an ongoing therapeutic nurse–patient relationship is essential. It can be used to encourage the patient to self-manage, to have an active, rather than a passive role in their care and enable recognition with respect for the patient's expertise about their own illness.<sup>46–48</sup> Nursing attributes most valued by patients are listening, interpersonal skills, and empathy.<sup>44,49,50</sup>

Nurses involved at diagnosis of disease need to appreciate that patients may struggle at various stages with the loss of their healthy self.<sup>51</sup> This can affect the way the newly-diagnosed person with IBD gives, seeks, receives and processes information.<sup>52</sup> Worry, fear and their physical condition can affect their ability to process information, which needs to be shared in a way that information cannot be misinterpreted.<sup>52</sup> Reliable printed information, leaflet, or web-based materials are recommended to supplement verbal information.<sup>53–56</sup> In the absence of in-house patient information leaflets, nurses can utilise those developed by country specific IBD patients' associations.

Advanced IBD nurses may have the ability to provide expert advice to patients about their IBD, but all nurses need to be empathetic, active listeners with sufficient knowledge to give basic guidance on key areas of concern for patients. These areas include diet (with appropriate reference to specialist dietitians, who are members of the multidisciplinary IBD team), social problems, common symptoms and complications of IBD, aetiology of IBD, medication and related potential side effects, and surgical treatments.<sup>53</sup> The nurse can provide emotional support by enabling patients to express their concerns. Non-clinical issues can sometimes be overlooked in a routine medical encounter, and patients value the opportunity to be listened to and 'taken seriously.' The nurse may not, however, advise beyond their competency.<sup>37</sup> With awareness of available specialist resources such as Advanced IBD nurses, stoma nurses, dietitians, or counselling services, patient referral can be made where appropriate.

### 2.5. Fistulae

#### N-ECCO Statement 2E

In fistulating IBD, nurses have a role in ensuring patient comfort, protecting skin integrity and managing complications. This can best be achieved by working in collaboration with the wider multi-disciplinary team (MDT) including stoma care therapists and tissue viability teams [EL5]

Fistulating CD is defined as the presence of fistulae, often arising in the perianal area as a communication between the intestine and perianal skin, or the abdominal wall, or other organs.<sup>57</sup> Five aspects have been identified as important for planning the management of fistulae: i. identification or exclusion of local sepsis; ii. assessment of nutritional status; iii. location and anatomy; iv. evaluation of the originating intestinal loop; v. determining organs affected by the fistula and their contribution to systemic systems or impairment of HRQoL.

Management of fistulae remains one of the biggest challenges for all who care for patients with IBD. A combination of

medical, surgical, nursing, nutritional, radiological and other specialist intervention may be required in the management of these disease complications. Development of enterocutaneous fistulae are typically secondary to a local inflammatory process often compounded by surgery and can result in significant morbidity for patients, including fluid and electrolyte disturbance, abdominal pain and sepsis.<sup>58</sup> Management of enterocutaneous fistulae is, therefore, considered to be a complex, multi-disciplinary team (MDT) challenge often requiring referral to a specialist centre.<sup>57</sup> The role of the nurse in the management of fistulae may include wound management, medication administration, containment of sepsis, support and liaison. The IBD nurse should not be expected to be an expert in dressings or wound managers which may be required for the management of specific types of fistula. However working in a collaborative way with appropriate health care professionals including stoma care therapists and tissue viability nurses, can help to enhance patient care and comfort.

Surgical intervention to perianal fistulae may include abscess drainage and seton insertion but can, in severe cases, require diversion surgery or proctectomy. It is notable that one postal questionnaire study addressed HRQoL in patients with severe perianal disease and found that overall HRQoL tended to be higher in patients who had undergone diversion surgery  $\pm$  proctectomy. However, it was also noted that the surgery itself had a potential impact on certain activities such as sports, swimming and sexual intimacy, highlighting the need for careful discussion and consideration which takes into account an individual's specific situation.<sup>59</sup> Identification of the impact of a fistula in terms of symptomology and effect on HRQoL can help in planning appropriate intervention. In addition, identification of underlying disease activity and resolution of this where possible can also help to improve outcomes.

Nurses need to provide education and signposting to alternative sources of support where appropriate. Despite this, there remains a limited amount of controlled evidence to guide nursing management of fistulising disease as the fistulae are often refractory to both medical and surgical interventions and have a significant impact on HRQoL.<sup>49</sup>

Examples of support available to individuals with fistulae include enabling careful, combined discussion between the patient, surgeon and specialist gastroenterologist (a second opinion might help and can be suggested without questioning the care of the original clinician). In addition, referral to patient support agencies, provision of information leaflets and diagrams and, in specific situations, the consideration of referral for more formalised counselling to help the patient manage their symptoms and the impact on their daily living.<sup>60</sup>

## 2.6. Diet and nutrition

### N-ECCO Statement 2F

Nurses need an awareness of potential nutritional issues in patients with IBD to ensure these are appropriately identified and managed [EL 2]. Patients and carers may require ongoing support and education from nurses regarding nutrition and especially in specific situations such as stricturing disease, or following surgery [EL 1]

Patients often ask about links between dietary habits and their IBD symptoms. However, epidemiological evidence to support diet as a risk factor is lacking. Patients with IBD need awareness of the importance of good nutrition in order to maintain maximum health, particularly as they may lose weight during episodes of active disease. It is important that nurses, physicians and surgeons (as well as patients) recognise that dietary advice is generally best provided by a dietitian with a special interest in IBD, who will often be found in the multidisciplinary team of a centre specialising in IBD. Generic or uninformed dietary advice may otherwise generate confusion for patients. Some general principles are, however, important for all members of the IBD team and for the patient to understand.

There is no specific diet that works best for all patients. It remains unclear whether dietary adjustments have a role solely in symptom control, or whether complete remission may be possible using dietary interventions in combination with pharmacological agents.<sup>61</sup> As no special diet has been found to be effective in the treatment of adult IBD, patients should be encouraged to follow a normal, healthy diet and lifestyle as tolerated. In some patients, however, diet may need to be tailored to meet individual needs based on symptoms and patient preferences.<sup>62</sup> Specific dietary advice may be required in the management of those with a concomitant irritable bowel, strictures, following surgery and stoma formation, short bowel syndrome, osteoporosis, anaemia, or genuine food allergies.<sup>63</sup>

Access to appropriate dietary assessment and specialist advice is important to patients with IBD. During the course of their illness some patients may experience general malnutrition or specific deficiencies of individual nutrients. A multitude of factors, including drug–nutrient interactions, disease location, symptoms, and sometimes inappropriate dietary restrictions can lead to nutritional problems impacting on health, nutritional status and HRQoL. This is not isolated to periods of active disease, since a wide range of nutritional and functional deficiencies can be evident after long periods of remission.<sup>64</sup> The most common nutritional deficiencies in IBD are macronutrients (calories, protein and fat), vitamins (e.g.: B12 and D), folic acid, and minerals (iron, calcium, magnesium, selenium, zinc) relevant to anaemia and osteoporosis.<sup>65</sup> The use of complementary or alternative medicines (CAM), nutritional supplements (vitamins, mineral and trace element preparations), herbal and homeopathic remedies, should always be discussed with the treating healthcare team.

The impact of inadequate nutrition is more noticeable in the growing child or adolescent. Dietary aspects should be taken into particular account in the paediatric population, since nutritional deficiencies can lead to a risk of growth failure, delayed puberty, bone demineralisation or significant psychosocial complications.<sup>57</sup> For children with IBD, nutrition is an integral part of management. The treatment of choice for active paediatric CD is nutritional therapy in which all of the patient's requirements for energy, protein and other nutrients are met by a nutritionally complete liquid diet. Exclusive enteral nutrition (EEN) is an effective therapy for small and large bowel disease, inducing response in 60–80% of cases.<sup>66</sup> There are many benefits in considering EEN as first line treatment in children with acute CD: it proves an alternative to pharmacological treatment, helps

to reverse weight loss and growth failure, may be better tolerated than steroids and compliance is often better than EEN in adults.<sup>57,67</sup>

Liquid feeds are, nevertheless, often found unpalatable and a finebore nasogastric (NG) tube can be used. The child and family can be taught how to insert and manage the tube, and how to follow the feeding regimen. When an NG tube is required for school age children, liaison with the local community nurse and/or school nurse should occur to ensure the therapy does not disrupt the child's education.<sup>68</sup>

## 2.7. Incontinence

### N-ECCO Statement 2G

Nurses should appreciate the impact of incontinence on HRQoL. Management of faecal incontinence should be tailored to the needs of the individual. Formal specialist referral for assessment and investigation may be appropriate [EL2]. Specific interventions with IBD patients can be beneficial such as pelvic floor exercises, evacuation techniques, dietary advice or information on continence products [EL1]. It is important to manage patient expectations of care and outcomes realistically and sensitively, taking lifestyle factors into account. During hospital admission supportive interaction including appropriate toilet access and ensuring privacy and dignity is essential [EL 5].

Faecal incontinence (FI) can be a significant problem for patients with IBD, affecting an individual's physical, psychological and social life. Fear of incontinence can leave IBD patients housebound and unable to work.<sup>23,69</sup>

Often patients find it difficult to find the right words to reveal or discuss their bowel symptoms openly. In order to do so properly addressing the issue of FI, the stigma surrounding it needs breaking down.<sup>70</sup> Patients need to be encouraged to ask for help if they require assistance and nurses, simply by asking about symptoms, can encourage patients to talk about continence issues. Nurses have a vital role in helping patients to manage and improve the symptoms of FI. Strategies include information, along with emotional and instrumental support. Nursing interventions in the management of FI may also include pelvic floor muscle exercises, perianal skin care, bowel retraining, medication (such as anti-diarrhoeals), dietary management, behavioural therapy (biofeedback), practical devices (including anal plugs and pads), and electrical stimulation. These interventions have not yet been evaluated in an IBD cohort specifically, but it is possible such practical support, along with optimisation of IBD treatments, will improve symptoms. It is crucial for the IBD nurse to be aware that not all patients will respond to the same nursing intervention. Therefore a tailored care plan should reflect the needs of the individual taking lifestyle factors into account.<sup>71</sup> Specialist referral to

local biofeedback or continence services, where appropriate, is recommended.

## 2.8. Sexuality and IBD

### N-ECCO Statement 2H

Issues relating to sexuality may cause anxiety and concern for patients with IBD. Nurses identifying problems regarding sexual function and sexuality need to be able to support and refer as appropriate [EL5].

IBD commonly affects individuals during young adulthood and an individual's sexuality and self confidence can be affected significantly by a diagnosis of IBD. Sexual functioning is a marker for HRQoL. IBD can have a direct and indirect impact on a person's body image, sexual functioning and interpersonal relationships.<sup>72,73</sup>

Emotional aspects may include concerns about body image, or worry about urgency or inappropriate leakage during intercourse. The unpredictability of the disease and fear of unexpected symptoms can lead to low self image or self esteem.<sup>74</sup> In order for sexual difficulties to be treated they need to be identified.<sup>72</sup> Although there is a paucity of data in this area, the available literature identifies high levels of sexual impairment reported amongst both male and female patients with IBD with just over half reporting that their IBD had impacted negatively on their relationship status.<sup>73</sup> Surgery appears to increase this negative impact in both males and females, particularly following proctectomy.<sup>72</sup> Libido was felt to be decreased in just over half the respondents, equally affecting both patients with CD or UC.

Busy workloads and changing personnel can make the introduction of discussions regarding sexuality difficult to initiate in clinical practice. However, the nature of the IBD nurse/patient relationship can foster the confidence and environment for these concerns to be raised. Facilitating time and fostering long term relationships with patients is a significant aspect of the Advanced IBD nurse role, and can promote discussions and enquiry.

The role of the nurse varies from allowing enough time during consultations for concerns to be raised, signposting towards information and offering advice, to identifying when there is a need for more structured support or specialist counselling. Tactful prompting and open discussion will identify the level of support needed.<sup>75</sup> No formal tools for measuring the impact of IBD on an individual's sexuality exist, but this may be beneficial in promoting an individualised approach to each situation.

Helping gay, lesbian, bisexual and transgender (GLBT) patients solve problems associated with sexuality and chronic illness requires nurses to understand and feel comfortable discussing aspects of sexual practices of this patient group.<sup>76</sup> Nurses who feel under-informed can refer to the extensive literature on GLBT experiences within healthcare settings.<sup>77-79</sup>

## 2.9. Fatigue

### N-ECCO Statement 2I

Nurses may be well placed to identify, acknowledge and provide treatment and support for patients with IBD experiencing fatigue. Causes of fatigue may be multifactorial and nurses, through discussion, may help patients to manage [EL 5].

The disease course of IBD is characterised by both intestinal and extra-intestinal complaints and episodes of active and quiescent disease. During a period of relapse patients frequently complain of fatigue. Even in remission, more than 40% of IBD patients suffer from fatigue.<sup>80</sup>

Piper et al.'s definition, describing chronic fatigue as 'unpleasant, unusual, abnormal or excessive whole body tiredness which is disproportionate to or unrelated to activity or exertion and present for more than a month', is widely used.<sup>81</sup> Chronic fatigue, not dispelled easily by sleep or rest, can have a profound negative impact on the person's quality of life.<sup>82</sup>

The aetiology of chronic fatigue can be multifactorial. Physical assessment, biochemical and haematological testing can provide possible explanations. Persistently low iron stores, haemoglobin, vitamin D, or raised inflammatory markers in the absence of bowel symptoms are examples of reversible causes of fatigue. Adrenal insufficiency or hypothyroidism are other potential causes. IBD nurses can monitor this in patients and provide advice on management. A 2004 review suggested that one third of patients with IBD suffer from recurrent anaemia and that this might contribute significantly to fatigue in this patient group. The authors suggest that anaemia should be actively sought and treated, using intravenous replacement if necessary in order to minimise GI side effects, increase absorption and improve quality of life.<sup>83</sup> Conversely, a large Scandinavian study found that fatigue was not associated with anaemia and/or iron deficiency.<sup>34</sup> This demonstrates the importance of an holistic assessment of fatigue. Psychological factors and HRQoL should also be explored. Psychiatric conditions can coexist with physical illness, and literature suggests this may be the case in IBD, with the prevalence of mood disorders such as anxiety and/or depression in IBD possibly up to three times greater than in the general population.<sup>84</sup> Chronic fatigue is associated with increased levels of disease-related worries and concerns in IBD, which in turn are associated with impaired HRQoL.<sup>35</sup> Questionnaires, such as The Rating Form of IBD Patient Concerns and The Fatigue Questionnaire, can be used to quantify other aspects of living with chronic illness, although no specific fatigue assessment for IBD currently exists.<sup>11,85</sup>

Fatigue is an important feature of IBD even when in remission. Studies looking at HRQoL in IBD populations indicate the prevalence of fatigue is higher than the general population, but little research exists which defines the severity of fatigue in this patient group, or identifies the relevance of any possible contributory factors.<sup>34,86,87</sup>

Once fatigue has been identified as an issue, it is important for nurses (and doctors) to monitor the individual to determine any improvement or worsening of the symptom, as this can fluctuate over time. The chronic nature of IBD makes it important for health care professionals managing individuals to adopt a holistic approach to disease management.

If biochemical, haematological, or endocrine causes are excluded, the nurse can work with the patient to identify steps and coping mechanisms which may help to manage the fatigue, with strategies such as: taking short naps during the day; reducing night shifts; exercising regularly; getting a good night's sleep; eating a well-balanced diet and keeping well hydrated.<sup>88</sup>

## 2.10. Pain management

### N-ECCO Statement 2J

Nurses may be well placed to identify, acknowledge and provide treatment and support for patients with IBD experiencing pain. Causes of pain may be multifactorial and not always linked to disease activity. Nurses, through discussion and collaboration with MDT, may help patients to manage this symptom [EL 2].

Abdominal pain is a common feature of IBD and often is the first symptomatic presentation of newly-diagnosed or exacerbating disease.<sup>6,10,89</sup> It can influence HRQoL and anxiety due to its unpredictable nature and difficult management.<sup>27,90</sup> The mechanism of pain may be inflammatory such as stricturing disease, fistulae, and fissures, or non-inflammatory such as adhesions, fibrotic stricturing disease or co-existing functional GI symptoms. Extra-intestinal factors including gall stones, renal calculi, pancreatitis or joint and skin complications may also cause symptoms of pain.<sup>57,91</sup> Complaints of pain should trigger further investigations to uncover the cause. These may include blood tests, imaging, endoscopy, or faecal calprotectin.<sup>89,90</sup> A sub-group of patients will continue to experience pain despite there being no evidence of active disease on investigation,<sup>90</sup> and in this case it is essential for the nurse to provide empathy and support the patient to manage their pain. This may be a manifestation of anxiety and depression or related to functional symptoms such as Irritable Bowel Syndrome.<sup>84,89,92,93</sup>

The nurse, administering medications must ensure they have a wide knowledge of pharmacological pain control methods, and associated side effects and drug interactions of the mainstay analgesics that may be used in IBD patients.<sup>89</sup> The psychological burden of pain should be recognised and addressed by clinicians. Therapeutic options such as optimising IBD therapy may help. The use of opioids in managing pain is complicated by side effects and dependence from chronic use.<sup>90,94</sup> The use of opioids has been found to increase mortality, serious infection and cause complications such as narcotic bowel syndrome, characterised by abdominal pain of unexplained nature or intensity that worsens with increased doses of opioids, and gut dysmotility.<sup>95,96</sup> Opioids should, therefore, be used with caution. Tricyclic anti-depressants may be useful as an

adjuvant analgesic to treat IBD symptoms.<sup>90</sup> Once the cause of pain is established, patients should be educated on the cause of their pain and, in conjunction with the MDT and pain management teams, empowered to recognise and proactively manage their pain, for example by taking regular analgesia.<sup>97</sup> Cognitive and behavioural psychotherapy may help patients to cope with pain and improve their quality of life and functioning.<sup>90</sup> A treatment algorithm for pain in IBD can support decision making in clinical practice.<sup>90</sup>

### 3. Advanced IBD Nursing

#### 3.1. Definition and requirements

In this document the term 'Advanced IBD Nurse' refers to experienced nurses practicing at an advanced level caring for patients with IBD (whether adult, adolescent or paediatric). This level of practice is "evident of being beyond that of first level registration" and would normally be attained following a combination of extensive clinical practice, professional development and formal education.<sup>98,99</sup>

##### N-ECCO Statement 3A

The Advanced IBD Nurse is an autonomous clinical expert in IBD who is responsible for the assessment and provision of evidence based care planning, and treatment evaluation, and who provides practical information, education and emotional support for patients with IBD. They will practice within their own professional competency and accountability, supported by protocols or guidelines [EL 5].

Job titles which include the terms nurse specialist, clinical nurse specialist (CNS), nurse practitioner, advanced nurse practitioner, nurse endoscopist, or nurse consultant are often used to describe the Advanced IBD Nurse. Although the specifics of these roles will vary depending on national and local needs, the international literature suggests commonalities in the expected skills required to undertake these roles. These include competencies in advanced clinical skills (which may include undertaking procedures such as physical assessment, endoscopy, or prescribing); nursing expertise; the development of practice standards and provision of evidence-based care; ability to analyse, critique and evaluate evidence and outcomes; critical thinking; publishing practice innovations or audits; the development of original nursing research; leadership; education; and change management.<sup>98,100–103</sup> Although autonomous practitioners, they are likely to be supported by inter-departmental, national or international protocols or guidelines.

Advanced IBD Nurses work as autonomous practitioners in collaboration with their patients and MDT. They have important roles in the assessment, nursing diagnosis, treatment planning, evaluation, monitoring, surveillance, education, health promotion, practical and emotional support for a caseload of IBD patients within the scope of their own professional practice and limitations.<sup>104</sup> However, clinical

skills and expertise represent only one facet of the role of the Advanced IBD Nurse.

##### N-ECCO Statement 3B

The Advanced IBD nursing role includes education, research, service development and leadership. In order to achieve these skills a broad clinical experience and development of clinical competencies is ideally supplemented by postgraduate education [EL 5].

Although it is acknowledged that the largest proportion of the Advanced Nurses' time is spent in direct clinical practice, it is considered that, in order to fulfil an Advanced Nurse's role, they should be actively involved in the education, research and service development.<sup>98,101,103–105</sup> Individual role requirements, such as the authority to prescribe, order, or undertake investigations, or admit patients to hospital, will be dependent on individual hospital or department procedures, alongside national regulation and policy.

There is no consensus on the level of education such nurses should attain. Requirements will vary between countries and organisations, and may be governed by national professional standards and regulatory requirements.<sup>99</sup> It is generally thought that CNS's should have a degree at minimum, while those in advanced practice (for example those who are assessing, diagnosing and prescribing treatment) should be educated to Master's level, while consultant nurses or senior university educators should have a Doctorate. Each hospital is also likely to have its own expectations and objectives for individual specialist nursing roles. The development of explicit clinical competencies is often advocated as a means to achieve the necessary advanced skills.<sup>102,103,106</sup>

Research is a recommended core activity of the advanced nurse role, but only 4% of time is dedicated to it, compared to between 60 and 70% of time spent on direct clinical care.<sup>98,103,105–107</sup> Lack of dedicated time is often cited as one barrier to integrating research into the role. Therefore it is essential to ensure this component is acknowledged in role descriptions and job plans. Nurses often feel they lack the skills or confidence to conduct research.<sup>108</sup> There are, however, many ways to get involved in research and develop knowledge and skills. These may include working with the research team to identify potential recruits for currently-running nursing or medical studies, identifying areas for future research based on clinical experiences, or, indeed, the development of original research questions and managing each step of the research process.<sup>109</sup>

A criticism of nursing as a profession and those in advanced IBD nursing roles in particular, is that there is little empirical evidence to support their value and contribution to patient's outcomes.<sup>110,111</sup> A systematic review of the effectiveness of the Advanced IBD Nurse identified a need to develop common competencies, to establish educational requirements of nurses in these advanced roles and to prospectively explore the impact of IBD nursing interventions on patient outcomes.<sup>110</sup> There should be no divide between medical and nursing research, although nurses may ask questions with a different, quality of life focus, such



as the psychological impact of IBD, the effect on family, employment and education, and financial implications of disease, which are areas of concern for patients. These are all topics which Advanced IBD nurses are well placed to research and explore.

Leadership in health care is not confined to those in management roles. Components of effective leadership include practice leadership; role modelling; promoting patient safety; caseload management; evaluation of services or interventions; facilitating improvements or innovation; consultancy; being able to develop self and other; and change management.<sup>98,112</sup> Skills the Advanced IBD Nurse may use in leadership include problem solving, critical thinking, listening and engagement with the team or stakeholders.<sup>98</sup> Leadership is pivotal to effecting change in clinical practice. An evaluation of a nurse leadership programme showed leadership skills improved team effectiveness and translated into the provision of more patient-centred care.<sup>113</sup> It has been shown that the presence of an IBD nurse improves services and that improvements in service quality are often driven by the Advanced IBD Nurse.<sup>110,114,115</sup>

The Advanced IBD Nurse is frequently involved with policy, protocol and guideline development, either independently or with other team members. These can often form a framework to support the clinical activities of the IBD nurse, such as a protocol for IBD telephone or email Advice Lines (AL). These types of documents may be required by organisations for reasons of professional indemnity. However, it needs to be acknowledged that Advanced IBD Nurses work beyond protocolised care and have the freedom to use their clinical acumen, whilst acknowledging professional limitations and seeking advice where appropriate. Advanced Nurses should be knowledgeable about the wider stakeholder or strategic planning of healthcare resources that they work within (local, regional or national level) in order to direct their own service and provide appropriate patient-focused services based on their needs.<sup>116</sup>

Networking and sharing of practice is an important aspect of leadership. This may be within their organisation or in national and international groups. N-ECCO is one such example of an international nursing network which enables practice development and best practice from a number of countries to be shared. Some experienced Advanced IBD Nurses will be very active in these networks, presenting best practice and research findings.

### 3.2. Skills

#### N-ECCO Statement 3C

The Advanced IBD Nurse works as part of the MDT, enhancing patient care and the patient experience, providing efficient, holistic and accessible care [EL 5].

With growing numbers of patients with chronic illnesses, healthcare systems are increasingly challenged to provide necessary care and empower patients to participate in their management. Advanced IBD Nurses play a key role in helping

to meet these challenges.<sup>117</sup> A well established MDT has been identified as important for continuity of patient care as well as for professional collegiality. Nurses are key workers within the MDT and may have a coordinating role, with comprehensive knowledge of the patient's condition, the care and treatment plans and the continuity of these. The coordinating role may include facilitating communication within the MDT to reduce the risk of fragmented care.<sup>118</sup> Skilled nurses who are competent in the management of patients with IBD can influence how well these patients accept and understand their illness.

The role of the Advanced IBD Nurse has been identified as covering a wide range of skills and personal attributes, making a real difference to patient care. The most frequently described aspect of Advanced IBD Nurses' role is that they are 'always there', a constant and reliable source of contact providing timely advice. As well as having good listening skills, and trying to create time for patients to discuss their problems, Advanced IBD nurses' personal qualities and characteristics have been described as: kind, caring, understanding, available, empathetic, sympathetic, reassuring, calming, confidence, commitment and problem-solving power.<sup>44,119</sup>

Communication skills are an essential part of nursing care in general and for the Advanced Nurse in particular. Patient-centred care involves talking to patients as individuals, seeking to understand and respond to their needs and preferences, and inviting them to participate and help make decisions. Showing concern and empathy, treating patients respectfully, proceeding without hurry and assuring confidentiality, help to establish trust. Warmth and friendliness helps nurses establish a rapport with patients and ease their anxiety. Non-verbal communication—such as eye contact, facial expressions, gesture, and touch—is as essential as words to all of these behaviours.<sup>120</sup> Additionally nurses need advanced communications skills when dealing with patients who are mainly using telephone contact.

Advanced nursing practice achieves a high level of credibility. This is strengthened by continuing self-evaluation, a constant reference to patient care, an involvement in research and a contribution to practice-based theory and critical reflection in practice. Nurses have a distinctive way of thinking about their practice and a clear vision for the future of nursing. Advanced IBD Nurses also need to be able to identify the gaps in their own knowledge and skills; and access the wider resources available to them to improve their skills in order to maintain and develop a high quality of care.

### 3.3. Patient education

#### N-ECCO Statement 3D

The Advanced IBD Nurse assesses understanding and, informed by current evidence, provides education to patients with IBD and their relatives based on individual needs, preferences and coping ability. The aim is to enable and empower the patient to live with IBD [EL 3].

The ability of a nurse to provide information and education is an important consideration for patients and may need a variety of forms (such as group, individual, or include the involvement of relatives).<sup>121</sup> Patient education may need to be repeated and be supported by direct access to the MDT or other sources (e.g.: phone, written information, electronic means, and country-specific patient support groups). A wide range of information about IBD is available on the internet. The quality of this information varies greatly and should only be used as supplemental information to more individualised education.<sup>54,55</sup> Studies on structured patient education have, to some extent, shown an increase in the participants level of knowledge, but no significant effect on HRQoL.<sup>122–125</sup>

Since some patients choose not to participate in structured patient education, a broad range of alternatives has to be available. Information may be more successful in engaging people if a tailored approach is used.<sup>126</sup> Tailored education targeting subgroups of patients with IBD could be appropriate (e.g. gender specific, age groups, or behaviour of disease). A 2008 ECCO consensus on patient quality of care recommends delivery of patient-centred information to meet patients' needs, but does not specify how information should be provided.<sup>111</sup>

The Advanced IBD Nurse in particular, possesses refined assessment and communication skills and as a result plays a key role in the MDT, focusing education on enhancing IBD patient knowledge, adherence and empowerment. The Advanced IBD Nurse has the ability to screen patients and offer education and support, based on level of patient care and stage of treatment plan, providing a constant contact point for patients' needs.

Self-management programmes for patients with UC have been introduced and evaluated. There is no clear evidence that self-management either improves health or increases wellbeing, with two main studies showing no difference in the quality of life in self-management, despite earlier access to medical treatment in the event of a relapse.<sup>127,128</sup> Despite this, some groups continue to recommend that IBD nurses facilitate self-management.<sup>129</sup> Findings from a cluster-randomised trial in the UK evaluating self-management versus treatment as usual, found there may be reduced economic cost for patients allocated to self-management compared to usual treatment yet the health related quality of life actually worsened in both the control and self-management group.<sup>130</sup>

Education towards self-management complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition. As well as teaching problem-solving skills, a central concept in self-management is self-efficacy—confidence to carry out behaviour necessary to reach a desired goal.<sup>131</sup> The Advanced Nurse's role is important in working towards increasing an individual's self-confidence in their ability to manage their disease, thus helping them deal with feelings of helplessness and embarrassment that they experience. Self-help groups can provide a range of services to help the patient. These services include initial support at the time of diagnosis, continued support, including family help, provision of information, social activities and support for research into the treatment and prevention of the disease in question.

### 3.4. Information giving

#### N-ECCO Statement 3E

Nurses at an advanced level may provide expert knowledge and understanding of the evidence for standard treatments, as well as the role of Complementary and Alternative Medicine (CAM) relevant guidelines and Health Promotion issues, supported with written information where available [EL5].

Patients want to be sure that what they have read about IBD is reliable, regardless of the source. The nurse at an advanced level should be able to identify, analyse and classify relevant literature. The Advanced IBD Nurse is well placed to be actively involved in health promotion such as advocating smoking cessation or participation in surveillance programmes. IBD teams are encouraged to support patient organisations' educational and open forum sessions, allowing patients to become more involved in shaping local services.<sup>132</sup> Introducing patients to their local or national patient organisations is fundamental as there is evidence that support groups improve patients' knowledge of IBD, and increased disease knowledge has been associated with improved coping and adherence to treatment.<sup>125,133</sup> A survey of 74 recently-diagnosed patients investigated their need for information. After two months, the main source of information was the doctor and the internet, but two thirds of the patients indicated that they preferred information from a nurse specialist.<sup>53</sup>

Nurses at an advanced level may also use a risk analysis approach in discussion with patients, perhaps to explain the risk of smoking, but also to weight up the risks and benefits of treatment or a specific therapy, including CAMs or other unproven therapies.<sup>8,57,134</sup> Adherence to treatment and any combination of treatment with CAM should also be discussed. For patients with special needs (medical, cultural, mental, social), the Advanced IBD Nurse plays a key role in linking in with appropriate services in the MDT.<sup>135</sup>

### 3.5. Pregnancy and fertility

#### N-ECCO Statement 3F

The Advanced IBD Nurse needs to provide support and information for patients and partners prior to conception, throughout pregnancy and following childbirth. Liaison with other health care professionals may be necessary [EL 5] Discussions regarding pregnancy should be initiated, wherever possible, prior to conception [EL 5].

Pregnancy and fertility can be emotive and sensitive. For IBD management it can generate complexities, and patients often express concerns about issues such as potential heritability, using medications during pregnancy and breastfeeding, or best mode of delivery. ECCO has produced consensus on reproduction in IBD and guidance to support clinicians in the management of patients during pregnancy

and there are a number of review articles which also inform practice.<sup>91,136–139</sup> These documents provide an evidence-base to underpin medical and advanced nursing practice in the clinical management of people with IBD. All IBD nurses should be aware of these documents in order to support patient discussion and to help provide education and promote health.

Research suggests a significant deficit in pregnancy-related knowledge in women with IBD.<sup>140</sup> The position of the Advanced IBD Nurse within the team and the relationship they form with patients can often result in them being the health care professional with whom such matters are raised; they may provide a useful role in the support and education of male and female patients at the stages of family planning including contraception, during pregnancy, delivery, and post-natally, along with alleviating concerns about other issues such as heritability, delivery or breast-feeding. These issues are the subject of the ECCO Consensus on Reproduction and IBD.<sup>138</sup>

Women and men are often concerned about the potential effects of medications to foetal health. Nurses, with the appropriate knowledge, can support people to make appropriate choices based on the risk/benefit profile of their individual situation, in conjunction with their treating consultant.<sup>136,137,141</sup> Other resources such as the Food and Drug Agency (FDA) and local medicine information services can be further inform discussion, although it should be noted that the FDA recommendations on the safety of some drugs for patients with IBD in pregnancy differ substantially to expert opinion on both sides of the Atlantic.<sup>138,142</sup>

In general it is advised that patients are encouraged to have early discussion about pregnancy plans with their treating team in order that treatments can be assessed and optimised if necessary to maximise pre-natal health.<sup>138</sup> The Advanced IBD Nurse can work with the patient throughout her pregnancy to minimise risk of relapse and ensure review takes place at timely intervals. In more complex patients, such as those with perianal disease, and ileoanal pouch or those at high risk of future colectomy, it is desirable for the gastroenterologists and the obstetric team to work together to ensure the most appropriate decisions are made regarding delivery. Often nurses facilitate this type of team working, advocating for the patient.<sup>142</sup>

### 3.6. Transition

#### N-ECCO Statement 3G

Special consideration needs to be given to the care needs of adolescent patients with IBD. Adolescence is a challenging time with individuals undergoing life changes in addition to their clinical needs. Wherever possible, an Advanced IBD Nurse should be involved in a formal process for the transition of patients from paediatric to adult services, in keeping with agreed local transition models, addressing the physical, social, educational and psychological needs of the young person [EL 3].

All children with a chronic disease will need to be transferred to adult services at some point, with the age depending on local policy. Preparing young adults for this

process is very important as they need to develop a sense of independence and responsibility. Transition should be seen as an ongoing process rather than a one-off event.<sup>143</sup>

The aim of successful transition is to provide the best care possible that will allow adolescents with IBD to become as functional, healthy and well in adulthood as their disease allows. There are two conceptual elements: the child taking responsibility for his/her disease management from parents, and the adult gastroenterologist taking responsibility of the adolescent from the paediatric gastroenterology team.<sup>144</sup> Advanced IBD nurses are often central to the smooth and successful management of children with IBD and their parents, during the transition process.<sup>145</sup> Preparation, along with good communication, is crucial if young people are to engage and participate in the process of transition.<sup>146</sup> Transition needs to be tailored to an adolescents individual needs, e.g. the paediatric gastroenterologist should continue to follow those patients with delayed puberty who still have some potential to grow.<sup>147,148</sup> Young people need well-developed social, interpersonal and emotional skills to successfully enter the world of adult health care. It is a difficult period for a young person undergoing physical and emotional change to take on this role when they are handed over to an adult centre. It may also be difficult for parents, who may be unsure of their role and responsibilities in this new setting.<sup>149</sup>

A stepwise programme for care transition, aimed at coaching the adolescent patient into self-management will benefit patients, parents, and the 'adult gastroenterologist' who will take over the care from the paediatric gastroenterologist.<sup>150</sup> There are a number of tools and models which support adolescent transition and guidelines for transition of patients with IBD have been published in the US and in the UK.<sup>144–150</sup> The model chosen for transfer will depend on local resources. Whichever model is chosen, continued audit is imperative to ensure outcomes are improved and maintained.

### 3.7. Biological therapies

#### N-ECCO Statement 3H

The Advanced IBD Nurse involved in the management and delivery of biological therapy is in a position to ensure that appropriate screening and identification of any contraindications to therapy are identified and recorded. Adhering to country-specific guidelines and local protocols enhances safe administration [EL 5].

Ideally the choice of biological agent should be guided by patient preference, but in reality this may be influenced by a number of factors including physician experience, local funding arrangements, previous response to therapies, and disease phenotype.<sup>7</sup> Studies have shown that patient's under-estimate the risk of lymphoma with biological therapies and have high expectations of duration and extent of remission. It is therefore vital that education regarding these aspects of care is addressed when trying to managing patient expectations.<sup>151,152</sup>

The Advanced IBD Nurse is best placed to facilitate such education and ensure information is conveyed in an

uncomplicated manner. The use of decision aids such as the Paling Palette are useful when discussing adverse events as they present evidence-based data in a pictorial form, comparing risk to situations that patients can easily relate to, and enhancing their understanding.<sup>153</sup> Biological therapies increase the risk of opportunistic infection so pre-treatment screening is of utmost importance. Evidence based guidelines exist and should be incorporated into clinical practice prior to initiating biological therapies.<sup>154</sup> All patients should be carefully screened to ensure that specific drug inclusion/exclusion criteria have been reviewed prior to administering biologics. Screening should involve a combination of blood monitoring, radiologic and risk assessment including immunisation history and relevant co-morbidities e.g. cardiac history. In the situation of home administration, patients should be counselled about the risks of opportunistic infections. It is important that patients are made aware of their responsibilities to report infections and attend for monitoring. Screening results may require onward referral by the nurse to other specialities such as respiratory or infectious diseases. Any nurse involved in the administration of biological therapies should be skilled and competent in the administration and management of infusions and educating patients how to self-administer.<sup>155</sup> When teaching patients to self-administer biological treatment, a training plan and assessment of the patient's ability and competence are essential and should be well documented. Nurses need to be aware of treatment side effects, how to manage infusion reactions, and must support their practice with evidence-based protocols.<sup>132,156</sup> Checklists are a good safety measure for documenting that key pre-treatment steps have been addressed. The Advanced IBD Nurse should use their expertise to influence IBD care beyond direct patient contact, for example, to facilitate teaching general ward nurses to administer biological therapies or developing link nursing roles.<sup>157</sup>

Assessment of patients' clinical response to biological therapies, along with monitoring of side effects, potential complications and biochemical response, can be undertaken by the Advanced IBD Nurse following agreed protocols either at the time of administration or at follow up.<sup>158</sup> Some centres undertake this in the context of a Virtual Biologics Clinic which allow multidisciplinary review and management of patients on biologics.<sup>159</sup>

### 3.8. The nursing assessment

#### N-ECCO Statement 31

The advanced IBD nursing assessment is both wide ranging and able to focus on specific areas of concern. The nurse may use biomarkers, imaging and physical assessment including endoscopy providing appropriate training has been undertaken. The Advanced IBD Nurse needs to be aware of existing assessment tools that may be useful aids in the management of patients with IBD and their related health problems [EL 5].

Most nurses will have been trained in the use of the nursing process which gives a framework for the care of a

patient.<sup>160</sup> In order to make a plan of care for any patient in any situation whether face to face in clinic, over the telephone or via email a thorough, competent and relevant assessment is vital.<sup>105,161–163</sup> The purpose of the assessment is to determine and record care needs and current health status which is to be used as a basis for planning, and determining the response to treatment and/or interventions. Nurses trained using a bio-psycho-social approach to assessment may divide their assessment into these categories. Other methods may be utilised but any approach needs to include the following: disease and health history (including co-morbidities, medication and any use of CAM, efficacy of treatment and drug side effects); current disease activity including extra-intestinal manifestations; dietary history; HRQoL; coping strategies and health behaviours e.g. smoking, drug adherence; psychological well-being and social support, and disease related knowledge.

At the first meeting with a patient it is helpful and necessary to gather a comprehensive 'IBD history'. This may include age at diagnosis, extent and duration of disease, any surgical procedures, current and past medication, any drug side effects or intolerances, dietary triggers or intolerances. It is also important to gauge the patient's understanding of IBD, its management and the care they are receiving. In taking the time to carry out this holistic assessment, the Advanced IBD Nurse is often best placed to identify what have been termed 'un-promoted issues in IBD' including the presence of functional GI disorders, problems with sexuality, fertility, drug monitoring and compliance, incontinence, fatigue and anaemia.<sup>164</sup>

It is helpful to use a validated disease activity scoring system to aid the consistent assessment of disease severity by which treatment decisions may be made. It may also enable improvement or deterioration in the patient's condition to be measured objectively, and help with audit and research. Several validated clinical scoring systems can be used in clinical practice, such as the Harvey Bradshaw Index for CD, or Simple Clinical Colitis Activity Index for UC.<sup>165–167</sup> Furthermore, the Advanced IBD Nurse may use other assessment methods such as abdominal examination, endoscopy, interpretation of blood results and other biomarkers, interpretation of radiology, histology and other imaging tests, all according to training, skills and local protocol.<sup>168</sup>

During assessment, the presence of any fever, nausea, vomiting, weight loss, fatigue or other signs indicative of active disease should be noted. In assessing a patient's psychological well-being and HRQoL it may occasionally be helpful to use an objective measure such as the Inflammatory Bowel Disease Questionnaire or the Hospital Anxiety and Depression scale.<sup>169,170</sup> Other scoring tools may be appropriate in certain situations, such as pain or fatigue scores. In all cases, where possible, there has to be consistency within local practice. An assessment proforma can be developed by the Advanced IBD Nurse for use during outpatient consultations or when conducting telephone assessments.<sup>162</sup> Such proformas help ensure a consistent approach to assessment and can be used by any level of nurse.

As IBD impacts upon the patients' social function, the Advanced IBD Nurse can assess the patients' existing resources both within the family and wider social structure. Despite reporting similar levels of stress that are unrelated

to work, patients with IBD have a lower employment rate, higher disability rate and more days of sick leave compared to the general population, but have enhanced social support.<sup>171–173</sup> The Advanced IBD Nurse needs to have some knowledge regarding national law for work environment for citizens' having a chronic disease, and should be able to refer the patient to additional support, if needed.

### 3.9. The Advanced IBD Nurse role in the follow up of IBD patients

Advanced IBD Nurses are involved in the care of IBD patients over a long period of time as the natural outcome of being a consistent team member and working with clients who have a lifelong condition. This continuity has been suggested as one of the advantages, over other staff groups, such as specialist registrars for their involvement in follow-up.<sup>174,175</sup> Since the role of the Advanced IBD nurse is pivotal to the provision of expert nursing care<sup>163</sup> nurses have a role in the follow-up of patients during relapse as well as in remission, providing a link between the family doctor and hospital care, providing rapid access in the event of a flare up.<sup>176,177</sup>

#### N-ECCO Statement 3J

The Advanced IBD Nurse who reviews patients independently of medical colleagues has an added responsibility to raise any issues of concern that fall beyond their scope of practice with appropriate colleagues, and need to be aware when it is necessary to refer patients on [EL 5].

However autonomous in their practice, the Advanced IBD Nurse will undoubtedly identify problems and issues which they are not knowledgeable or competent to treat and manage. In order to maintain accountability and deliver a safe service, appropriate medical support should be available to consult with and provide support in the event of new findings or complex cases. The Advanced IBD Nurse will also have an understanding of the potential EIM's of IBD such as joint, skin or eye problems, be able to recognise symptoms resulting from these, and know when to refer on to relevant associated specialists.<sup>178</sup>

The Advanced IBD Nurse may also play a key role in identifying actual or potential psychological problems.<sup>16,179</sup> Patients with IBD have a higher rate of anxiety and depression compared with the general population.<sup>30,180</sup> Patients who seek psychological support are more likely to be females with concerns regarding: burden of disease, pain, suffering, financial problems and sexual performance.<sup>181</sup> Newly-diagnosed patients, or those with disturbing symptoms or having undergone surgery may need special attention.<sup>182</sup> The nurse may be able to identify IBD patients with increased risk of having, or developing, anxiety and depression, and also needs to know what psychological support is available locally and how to access it.

### 3.10. The Advanced IBD Nurse role in managing Advice Lines

#### N-ECCO Statement 3K

Advice Lines are considered a key element of an advanced IBD nursing role and may improve clinical and service outcomes [EL4]. This type of contact is suitable for providing many aspects of care, including information and support, and the assessment, investigation and treatment of the unwell patient [EL5].

The most frequently-cited benefit of an IBD nursing service from the patient perspective is an access point for prompt resolution of relapse.<sup>44,183,184</sup> It has also been described as an element of "best practice" in an observational study involving audit and questionnaires in eight European countries and a 'lifeline' in one qualitative study of patient follow-up care needs.<sup>175,185</sup>

As well as the treatment plan, there are many other facets of life for the patient and challenges continue through different stages of, as well as changes in, the condition. Issues around schooling and employment, smoking, diet, pain, fertility and pregnancy, travel, sexual and other relationships, medical compliance, stigma, transition from childhood to adulthood, fatigue and more may be addressed via a telephone or email Advice Line (AL).<sup>141,186–189</sup> Advanced IBD nurses are in a good position to have access to appropriate information and to be able to direct a patient appropriately.

ALs, as part of an IBD nursing service, can reduce visits to outpatients and length of inpatient stay.<sup>188</sup> AL services can negate the need for some face to face reviews, but may also be perceived as a means of keeping patients away from outpatient clinics.<sup>190</sup> One aspect of the AL is to provide prompt access to clinics when clinically appropriate, as occurs in other specialist services such as diabetes nursing.<sup>191</sup> It is important, therefore that an IBD service not only manage the AL but also be able to provide other aspects of support surrounding the service such as adequate consultant support and urgent clinic slots, in order to function effectively.

Some studies have suggested that AL increased remission rates. However, study reliability may be questioned and it cannot be directly inferred that the AL was the causative factor in the improvement in care.<sup>174,184</sup> Still, it is acknowledged that having an AL service supports an efficient and safe IBD service.<sup>192–195</sup>

It is essential that advanced communication skills are utilised when using remote assessment especially as non-verbal cues cannot be used.<sup>196,197</sup> For example, the UK General Medical Council guidelines for prescribing over the phone or via other non face-to-face methods outline some helpful parameters to ensure safety when doing such assessments.<sup>198</sup> Emphasis is placed upon appropriate competency and knowledge of the practitioner, establishing a current history in context of the past, the importance of documentation, and passing on the consultation appropriately.<sup>198,199</sup> Different levels of autonomy will accompany different experience, competency and qualification. Services

must also consider the above in the light of local policy, training, protocols and legal confines.

It should also be noted that the nurses managing an AL should be sufficiently experienced and competent to identify the patient's needs and redirect as appropriate. Enquiries or concerns may not all be IBD-related. Protocols should be developed so that nursing and medical staff have agreed expectations of an AL service.<sup>185</sup> Local protocols will reflect local practicalities and legalities. Protocols should outline the aim, lines of responsibility, and the remit agreed for those involved in running an AL.<sup>118,200</sup>

### 3.11. The IBD nurse role in the planned review and care of stable patients

#### N-ECCO Statement 3L

The Advanced IBD Nurse can conduct patient reviews face to face, via telephone consultation or by electronic means [EL4]. If carrying out non face-to-face assessments the Advanced IBD Nurse must be aware of the limitations of this type of contact and use skilled judgement in knowing when further review may be needed. Regular review enables the IBD nurse to monitor the patient, their treatments, and arrange appropriate investigation as required [EL 5].

Definitions of 'remission', such as detailed in the ECCO Consensus guidelines for UC and CD, apply to a person's state at any given period of time.<sup>6-8,10</sup> and this is part, but not the entirety, of the definition of the 'stable' patient referred to here. Individual services will need to clarify what they define as 'stable' by considering aspects such as current medication and past medical history alongside the type of follow-up they are able to provide. It is important to recognise that there are many potential settings in which a nurse may review patients who are considered stable, whether in remission or on stable treatment which is being adequately monitored such as face-to-face clinic in the outpatient setting, over the telephone, as well as virtual clinics (see Section 3.7).

The routine review of stable patients has been cited as part of the incentive to setting up IBD nursing services. In some studies it is suggested as an alternative to address the limitations of time and space in outpatient consultations with medical staff and resulting in the reduction in the number of outpatient clinic appointments needed.<sup>174,176</sup> As with AL assessment by telephone, it is advised that the same systematic approach to assessment is followed. It should also be added that yearly follow up clinics are a valuable opportunity for assessing the impact of the disease on HRQoL which may alter over time.<sup>36,195</sup>

The aim of long term follow-up in IBD is to assess the safety and efficacy of IBD therapy, thorough assessment of disease activity, monitoring of adverse events and side effects. This also encompasses reviewing laboratory tests, arranging screening examinations such as surveillance endoscopy for colorectal cancer, assessment of patients' HRQoL addressing resources to improvement compliance and coping, and assessment of patients' and families' needs.

With regard to medication review, it is important to ensure that treatment remains appropriate according to current guidelines. Follow-up is also important for assessing and encouraging good treatment compliance and appropriate monitoring.<sup>174,176</sup>

It must be recognised that the role of the Advanced IBD Nurse should not be divorced from the MDT. The level of availability of, as well as expertise from, medical professionals should be considered when setting up follow-up clinics, as the team support and accessibility is imperative for the safe running of such services. The Advanced IBD Nurse may have an autonomous role but this ideally is as part of the wider multidisciplinary team.

#### N-ECCO statement 3M

The Advanced IBD Nurse has a responsibility to document clearly and communicate where relevant beyond the direct MDT, adhering to country specific policy. Regular audit and survey to review process and ensure quality is recommended [EL5].

It is important to ensure that accurate and comprehensive documentation is recorded in a manner and place that are accessible to all relevant members of the MDT.<sup>185,201</sup> It should be recognised that a growing number of centres are developing email or web-based consultation tools. As use of remote methods of reviewing patients are developed, the basic principles of communication and support need to be maintained. It may also be appropriate to restrict usage of these remote consultation methods to stable patients until the evidence base for safety of practice expands. It is strongly recommended that clinics should be based on a well-maintained database with good integration of IT systems and with both clerical and Advanced IBD Nurse support.<sup>202</sup>

As with ALs, protocols should be developed so that nursing and medical colleagues and patients have agreed expectations of this nurse-led service.<sup>185</sup> Local protocols will ensure that the practicalities and legalities of local practice are taken into account. Protocols should outline the aim, lines of responsibility, and the remit agreed for those involved in running the service.<sup>200,201</sup> Audit of the service must be undertaken to assess usage and ensure quality of care and patient experience.

## 4. The perspectives of IBD Nursing

### 4.1. The benefit of an Advanced IBD Nurse

#### N-ECCO Statement 4A

The Advanced IBD Nurse provides a pivotal and important role in the care of the IBD patient, which benefits the patient, the MDT, and the healthcare provider [EL 5].

Patients with IBD are positive about, and appreciate the role of, the Advanced IBD nurse.<sup>44</sup> Benefits identified for

patients include: increased access via telephone ALs and nurse-led clinics, especially at times of disease exacerbation; the ability of specialist nurses to appropriately assess, investigate, modify treatment, monitor and review IBD patients via treatment guidelines; provision of emotional and physical support; reduction in outpatient attendances and waiting times. Furthermore, the Advanced IBD Nurse can play an important role as case manager in the IBD team, providing an accessible point of contact for the whole team and their collaborating specialists.

There is evidence that IBD Nurses are carrying out significantly complex management of patients with IBD and this in turn releases resources and physician time to manage more complex patients.<sup>116</sup> Such involvement is recognised as an important contributor and supplement to the conventional follow-up of these patients.<sup>181</sup> The debate surrounding the future role of various health-care professionals in the management of patients with long term conditions, including IBD, has, in part, been prompted by the increasing incidence of these conditions, with subsequent demand on the healthcare system, as well as focus on health promotion and prevention. Despite the recognition that Advanced IBD Nurses are of clinical importance for the management of patients, the effect of such involvement on patient reported outcomes (PROs) remains scarcely studied. However, nurse-led follow-up has been shown to result in shorter time span from start of relapse to start of appropriate treatment.<sup>176</sup> There is emerging evidence from the UK IBD National Audit which demonstrate that IBD nurses, as part of a multidisciplinary team, help reduce hospital admissions, increase the proportion of people with IBD to self-manage and are pivotal in offering greater patient choice of care.<sup>203</sup>

Advanced IBD Nurses reduce direct healthcare costs when enabled to be pro-active in coordinating care within and outside of the hospital setting, but increased staff numbers are required to sustain these cost-effective benefits.<sup>204</sup> Education is a key role of an advanced IBD nurse, however this is not confined to patient education. A significant contribution can be made to developing the knowledge and skills of the fundamental IBD nurse in clinical areas such as out-patient departments, endoscopy units and hospital wards.

The views of patients with IBD are increasingly being heard via national patient organisations, with support at a European level from the European Federation of Crohn's and Colitis Associations. Advanced IBD Nurses have, through national and international bodies (such as the Royal College of Nursing (UK) and N-ECCO) represented these views, influencing practice, service delivery and have been drivers for change. These N-ECCO consensus statements are one such example of nurses' increasing sphere of influence.

#### 4.2. The need for high quality research on IBD nursing in Europe

##### N-ECCO Statement 4B

Further research is needed to assess the impact of IBD specialist nursing interventions. To achieve this, the Advanced IBD Nurse needs to participate in and conduct research activities appropriate to their role [EL 5].

Advanced IBD nursing interventions might provide benefit for IBD patients. However, a Cochrane review published in 2009 reported only one which suggested this. This particular study was assessed as low quality and the results of this study therefore, should be interpreted with caution.<sup>110</sup>

There is a vital need for higher quality trials of the advanced IBD nursing interventions in order to assess their impact on the care and management of IBD patients. More robust studies are needed in IBD nursing, and the current challenge for all IBD nurses is to produce the evidence which will demonstrate the relevance of their role in caring for patients with IBD. Collaboration with clinical academics and established IBD researchers can offer guidance and support and help overcome the initial difficulties in conducting empirical research. The next step would be to demonstrate that IBD nurses help improve desired health outcomes in patients. These two steps will require the design and implementation of research projects aimed at covering the gaps in knowledge, especially the association between nursing interventions and patient outcomes.<sup>205</sup> Collaboration through N-ECCO may be an appropriate means of conducting this research on a European wide scale to provide the best results.

## 5. Conclusion

The N-ECCO Consensus statements aim to provide practical value at a local, national and international level in the development of nursing care for patients with IBD.

These statements are intended to be used as a means of informing nurses, improving their knowledge and understanding and so raise the standard of care for patients with IBD.

The European nursing collaboration achieved with the N-ECCO Consensus statements provides a platform for future partnerships of nursing to perform research and other developments, which will in turn, raise the standard of care for patients with IBD across Europe.

## Conflict of Interest Statement

ECCO has diligently maintained a disclosure policy of potential conflicts of interests (Col). The conflict of interest declaration is based on a form used by the International Committee of Medical Journal Editors (ICMJE). The Col statement is not only stored at the ECCO Office and the editorial office of JCC but also open to public scrutiny on the ECCO website (<https://www.ecco-ibd.eu/about-ecco/ecco-disclosures.html>) providing a comprehensive overview of potential conflicts of interest of the consensus participants and guideline authors.

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