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ECCO Guideline/Consensus Paper

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Second 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

This is the second Nurses European Crohn's and Colitis Organisation [N-ECCO] Consensus Statements document addressing inflammatory bowel disease [IBD] nursing across Europe. N-ECCO continues to be an active member of the European Crohn's and Colitis Organisation [ECCO], providing education and networking opportunities for nurses across Europe within three designated nursing sessions, N-ECCO Network Meeting, N-ECCO School and the N-ECCO Research Forum, in addition to e-learning and podcasts.

1.1. Aim

The overarching aim of ECCO is to improve the care of patients with IBD through the development of guidelines, education and research. Current evidence is fundamental in enabling N-ECCO to meet this progressive aim. This document updates the first N-ECCO Consensus Statements based on the 'ideal' standard of care,[1] and provides additional statements and evidence supporting contemporary IBD nursing practice, while acknowledging the extensive variety in IBD nursing practice across Europe.[2]

1.2. Methods and results

The N-ECCO Consensus Statements required revision due to the emergence of new evidence supporting the role of the IBD Nurse. In line with Standard Operating Procedures set out by ECCO, the proposal to update the Statements was approved by ECCO's Governing Board. The ECCO Office sent an international call for N-ECCO members in January 2017; 10 nurses and the current N-ECCO committee of 2017 were selected and divided into four working groups [WGs] in March 2017, each responsible for a different section of the consensus document.

Each WG performed literature searches so as to enable review of the original Statements and to add new Statements. The electronic literature-search databases included AGRIS, Embase, Global health, HMIC, Journals @ Ovid full-text, OVID Medline [R] In-process Non-indexed citations, Medline, PsychArticles Full text, PsychInfo, Your Journals @ OVID EMBASE, CINAHL and the British Nursing Index via the OVID platform from 2010 onwards.

The consensus process was based on a modified Delphi method, a recommended method for determining consensus for a defined clinical concern.[3,4] The iterative method uses rounds of voting to determine consensus of opinion,[4] with participants debating the agreed Statements at the final voting round.[5] The updated Statements document was submitted to an online platform for discussion and for online voting by all national representatives of N-ECCO in May 2017, and 63% of national representatives and the Consensus Working Group voted. The voting indicated that 83% of the Statements had gained over 90% consensus, indicating that further online consensus rounds were unnecessary. Statements receiving <80% consensus were reviewed; for the second and final voting round, which took place in June 2017, the Consensus Working Group met and achieved 100% consensus agreement for all 31 Statements.

The Consensus Statements are divided into four sections. 'Fundamental IBD Nursing' details the basic nursing care required in order to meet the needs of patients with IBD, delivered by nurses working across many settings. The section 'Advanced IBD Nursing' pertains to nurses who have developed their knowledge, skills, research and expertise in IBD. 'Advanced IBD nursing care for particular situations' provides guidance on supporting patients with IBD who are facing special situations, and 'Benefit of an IBD Nurse', addresses the value and benefits of the specialist nurse within the IBD multidisciplinary team [MDT].

2. Fundamental IBD Nursing N-ECCO Statement 2A

> Nurses in contact with patients with IBD working in any setting need basic knowledge of the diseases, to know the difference between Crohn's disease and ulcerative colitis, and to appreciate the importance of establishing timely therapeutic interventions. Understanding of key diagnostic strategies and the main medical and surgical options available in the management of IBD is recommended [EL2].

2.1. Definition and requirements

IBD is an umbrella term for the life-long bowel diseases of ulcerative colitis [UC] and Crohn's disease [CD]. IBD is a global disease with a rising prevalence,[6,7] and it follows an unpredictable relapsing and remitting course. Common symptoms of active disease in both conditions include diarrhoea, abdominal pain, anaemia and fatigue.

Although the causes of IBD are unknown, it is recognized as an immune-mediated disease, possibly precipitated by various genetic and environmental factors, and it is advisable to read the ECCO Topical review on environmental factors in IBD.[8] Although IBD often presents in adolescence or young adulthood, 10–30% of patients are over 60 years old, either having aged with IBD or developed it in middle adulthood. Illness in older adults is often complicated by the physical changes of ageing, associated co-morbidities, and atypical presentations.[9] Paediatric forms of IBD are characterized by a more complicated disease course, with marked inflammatory activity and frequent need for corticosteroids and immunosuppressive therapy compared with adult-onset IBD.[10]

UC affects only the rectum and colon. Originating in the rectum, it can extend proximally to the sigmoid, descending or entire colon.[11] The inflammation is continuous and limited to the mucosa. Symptoms include rectal bleeding, passing mucus, abdominal pain, diarrhoea and faecal urgency, sometimes with incontinence. Location and severity of disease activity determines therapy options.[12]

CD occurs anywhere between mouth and anus. 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.[13] Initially an inflammatory process, CD can progress to a stenosing/stricturing or penetrating/fistulizing pattern, each adding considerably to disease burden, with a reported occurrence of perianal fistulae of 21–23% in population-based studies.[14]

Patients may develop extra-intestinal manifestations [EIMs], with up to 50% of patients with IBD experiencing at least one EIM; these may present before diagnosis and can affect joints, skin, eyes and liver.[15] Patients with IBD are at increased risk of developing colorectal cancer [CRC] in both UC and CD; the risk varies with the extent and duration of disease, family history of CRC, and presence/absence of primary sclerosing cholangitis [PSC]. Over the past 35 years, the risk of CRC in patients with IBD has not declined significantly, but the risk of dying from CRC has decreased.[16]

2.2. IBD diagnosis and treatments

Diagnosis is confirmed by clinical evaluation [patient history, physical assessment] and a combination of endoscopic, histological, radiological and/or biochemical investigations.[13] Inflammatory markers such as faecal calprotectin may also be used.[17] Endoscopy with biopsy of the colon and terminal ileum may confirm diagnosis. Computed tomography [CT] and magnetic resonance imaging [MRI] scans enable evaluation of disease extent, activity and complications.[12,13] A working knowledge of diagnostic procedures enables nurses to support patients with their questions about investigations and preparation for them.

Medical treatments aim to induce and maintain remission, and to improve health-related quality of life [HRQoL]. The complex choice of single or combined drug therapy is influenced by location and severity of disease, treatment availability, local experience, and individual patient circumstances [such as tolerance, side effects, drug interactions, pregnancy, and patient and clinician preference]. Detailed explanations of recommended medical treatments are available in current ECCO Consensus documents.[12,13]

Approximately 30% of patients with UC and up to 70% of patients with CD will require surgery at least once in their lives.[18,19] Surgery for CD may include small bowel resections, subtotal colectomy, temporary ileostomy, ileorectal anastomosis, or pan-proctocolectomy.[20] Iloecaecal resection is sometimes indicated for isolated terminal ileal disease, and surgery and endoscopy procedures may be necessary for treating strictures and fistulae. Surgical interventions for UC include restorative proctocolectomy with ileal pouch–anal anastomosis, subtotal colectomy with end-ileostomy, and subtotal

colectomy with ileorectal anastamosis.[21] Pouch surgery and pouch dysfunction is covered in Section 4 'Advanced IBD nursing care for particular situations'. Surgery may improve HRQoL in patients with CD and relieves patients with UC of unremitting inflammation, although EIMs can remain.[22] A consistent patient-reported fear is the potential need for a stoma,[23–26] although stoma-forming surgery may have significant benefits for HRQoL.[27–29]

IBD can have a significant negative impact on patients' HRQoL; prolonged disease activity, disease complications, the uncertain nature of IBD, and risk of developing cancer cause particular concern.[30,31] Alongside objective measures of disease, such as endoscopy results, patient-reported outcome measures [PROMs] are emerging as a means of gauging the impact of these concerns, and the effectiveness of interventions.[32–34] PROMs developed with patient and clinician input more accurately reflect the concerns of each and will become an important future aspect of assessing disease activity and the licensing of IBD-specific drugs.[32–34]

Timely therapeutic intervention is essential for disease control.[35] Nurses with a basic knowledge of IBD are advised to consult the Advanced IBD Nurse or gastroenterologist where appropriate, according to local referral procedures.

2.3. Impact of IBD on patients' lives

N-ECCO Statement 2B

Nurses caring for patients with IBD need an awareness of the immediate and long-term physical, social and emotional impact of the disease, including patients' key concerns, and the effect of IBD on HRQoL [EL3].

A major life impact is the need to be near a toilet. Urgency can be severe, with some patients reporting less than 30 s between calls to stool and actual defecations.[36] Fear of losing bowel control is so great that some patients always worry about where the nearest toilet is.[31,36,37] Recent evidence suggests that, at some point of the disease course, between 31 and 74% of people with IBD experience faecal incontinence,[36,38,39] not necessarily related to disease activity.[37] Despite it being a major concern, incontinence is rarely reported to or addressed by clinicians.

IBD can have an immediate and lifelong psychological impact.[40] Nurses can provide support and help patients to utilize appropriate tools so as to facilitate self-management. The immediate impact results from embarrassment, hospitalization, and fears and concerns about the uncertain origin and course of the disease[41] and the possibility of cancer.[41,42] Concerns about possibly requiring surgery and/or a stoma bag, body image, loss of bowel control, and producing unpleasant odours are particularly distressing.[43] During hospitalization, bowel control difficulties are more likely, due to relapse and shared toilet facilities with limited availability. Nurses can provide empathetic support and may be able to influence easier access to facilities. Discreet assistance and maintenance of patient dignity in the event of incontinence is essential.

Lifestyle impacts of IBD include self-imposed or professionally recommended dietary restrictions to control symptoms, and long-term medication to control disease, with patients constantly monitoring behaviours that may trigger symptoms.[41] There can be an ambivalent relationship with eating, including food avoidance, due to concerns about potential after-effects.[44]

Impact on daily activities may include absence from school or work, and difficulties meeting employment requirements. Patients may feel stressed about taking time off work due to IBD, and 40% make adjustments such as working from home, working shorter days or working part time.[30] Research suggests fatigue is the commonest reason for absence, with patients reporting insufficient energy to last through the full working day.[30]

As IBD is unpredictable, patients may have difficulty planning or engaging in activities, both of which are often influenced by toilet access and availability.[41] Social and leisure activities are negatively affected when patients have to avoid, make last-minute changes to, or cancel planned activities due to symptoms.[45]

Although necessary, receiving IBD treatment may have a negative impact as it reminds patients about their illness. Concerns range from side effects of medication, inconvenience and burden of taking medication, and financial burden. However, evidence suggests that strong social support networks in patients with a chronic illness can facilitate effective coping, positively influence health status and improve outcomes of disease.[46] Family support, particularly that provided by parents, plays a vital role in the development of children and adolescents with IBD.[47]

2.4. Psychological impact of living with IBD

N-ECCO Statement 2C

Nurses caring for patients with IBD need to be aware of the psychological impact of IBD, including anxiety, depression and distress, and offer onward referral to appropriate specialist support services if necessary [EL3].

The unpredictability of IBD symptoms causes numerous physical and psychosocial challenges for patients,[48] often independent of disease severity. IBD is a concealable illness, leading some to downplay the associated symptoms.[45] Many people feel stigmatized by IBD, often because it is a bowel disorder, which others may perceive as dirty,[49,50] or because of associated fatigue, which others may misintepret as laziness.[51] Some patients report feeling damaged due to physical changes associated with IBD or treatments. Self-blame regarding the onset of IBD can lead to poorer adjustment to the disease and reduced HRQoL during remission and relapse. Even in remission, background persistent disease-related issues such as fatigue, EIMs and sleep difficulties can be detrimental for HRQoL.[44,52]

One-fifth of patients experience depression and one third experience anxiety.[40] Routine screening for signs of psychological morbidity is recommended, with referral to formal psychological counselling and support for those patients demonstrating higher levels of concern.[40] Screening may be conducted using validated scales.[53–57] Interventions including cognitive behaviour therapy[57] and pharmacological agents such as selective serotonin re-uptake inhibitors may be beneficial. Mindfulness is a psychological skill linked to mental health and well-being, encouraging the patient to be aware of moment-to-moment experiences and avoiding excessive, unnecessary upset.[58] Mindfulness interventions aim to develop skills for managing stress and have been shown to improve mood and quality of life, with improvements sustained at 6 months post intervention.[58] Psychotherapeutic interventions may be beneficial for patients with IBD who have co-existing irritable bowel syndrome [IBS]-type symptoms.[59]

Disease-related distress is a phenomena distinct from psychological morbidities such as anxiety, depression or stress, and has been identified in other chronic diseases such as diabetes.[60] Disease-specific scales can be used to measure distress, identifying priority

issues for patients and informing delivery of supportive interventions.[61] Nurses can also reduce disease-related distress by providing patients with realistic expectations about the onset of therapeutic effects of medication and the transient nature of some side effects, including temporary worsening of symptoms, weight gain and sexual dysfunction.[57]

Some patients may struggle to disclose their diagnosis and symptoms to new potential partners, or find intimacy challenging due to sexual difficulties, fatigue and fear of incontinence.[62] Even if family members, partners and friends are usually supportive, there can be a lack of understanding.[63] Contact with other people with similar health problems may benefit patients.[64] Sharing experiences with others who 'know' what it is like to have IBD, can provide important social, emotional and psychological support.[65] Nurses can provide contact details for country-specific patient groups and charities. These fulfil an important supporting role for those dealing with a new diagnosis or major developments of established disease.

2.5. Patient advocacy and person-centred care

N-ECCO Statement 2D

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

An advocate promotes and supports the interests of others.[66] Advocacy is universally considered a moral obligation in all clinical 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.[67–69] Examples of advocacy in practice include respecting patients' rights, representing patients' interests, speaking up about patients' needs and viewpoints, and protecting dignity and privacy.[70] Some interventions for IBD, such as colonoscopy, may be worrying to some individuals. Advocacy in this instance requires the nurse to understand the concerns, needs and preferences of the patient and to assist the patient in meeting those needs or in overcoming concerns so as to allow them to receive appropriate health care. Advocacy and appropriate support may include ensuring urgent and timely referral to Advanced IBD Nurses, gastroenterologists or stoma nurses,[46] or assisting patients in voicing their concerns to the MDT.

2.6. Communicating with the patient with IBD

N-ECCO Statement 2E

Nurses need to develop an empathetic and active listening role, and be able to provide essential IBD-related information and holistic support [EL3]. Nurses have a role in facilitating communication between the MDT and the patient, enabling shared decision-making [EL3].

Verbal and non-verbal communication is vital in nursing; it helps meet patients' needs, and enables provision of support, advice, compassion, caring and empathy that is highly valued by patients.[46,71,72] Virtual contact with IBD Nurses via telephone and email clinics is recommended, enabling a more flexible and patient-focused approach to management.[73] Age-appropriate support should be offered by those who are best placed to meet the needs of patients and their family members or carers.[74]

In any chronic illness in which the individual will have an ongoing relationship with health-care professionals, communication facilitates rapport and trust.[75] The resulting therapeutic nurse–patient relationship can encourage the patient to have an active rather than passive role in their care, and to recognize their expertise about their own illness.[76–78]

Nurses should be empathetic, active listeners with sufficient knowledge for giving basic guidance on key areas of concern for patients. This may include knowledge about diet, social problems, aetiology of IBD, common symptoms and complications, medication and related potential side effects, and surgical treatments.[79,80] Patients value the opportunity to be listened to and 'taken seriously.' However, the nurse should not advise beyond their competency,[81] and should refer the patient to another health-care professional within the IBD MDT where appropriate.

Patients with IBD may struggle at various stages of their disease with the loss of their healthy self.[82] This can affect the way the newly diagnosed individual gives, seeks, receives and processes information. Worries and physical symptoms can also affect the ability to process information, and the nurse must share information in such a way that it cannot be misinterpreted.[83] Reliable printed information leaflets or web-based materials are recommended for supplementing verbal information.[79,84,85]

The method of communication and source of information may need adjusting to meet individual patient requests.[80] Patients may forget up to 50% of medication information provided, mostly recalling medication intake aspects. Techniques such as summarizing, categorizing, and supplementing consultations with written information may improve patients' medication knowledge and recall.[86] Patients who participate in their care and share in decision-making have appreciably better outcomes than patients who do not.[87] Similarly, patients who understand the benefits and risks of a disease management plan are more likely to accept it, and be more willing to share in and follow their treatment and monitoring schedules.[88]

Effective communication between physicians, patients, and members of the MDT across different health-care levels, is essential.[73,89] The best care for patients is delivered within an IBD Centre of Excellence, founded on current consensus,[88] and provided by an MDT with a named clinical lead.[74] An IBD MDT could comprise specialist gastroenterologists, colorectal surgeons and nurses, a dietician, a pharmacist, a pathologist, and a radiologist with a special interest in gastroenterology.[90]

Positive patient–clinician relationships with good communication are essential for optimizing the quality of care, health outcomes, and patient satisfaction with health care in chronic diseases.[91] Person-centred care is one way of providing better care and support for people with IBD. In this approach, the individual and their family is at the centre of care management, and the patient is recognized as an expert in their own health, enabling them to collaborate with health-care professionals in achieving the best outcomes. The patient is treated as an active and responsible partner, and their narrative is listened to.[92] New concepts and practices include 'patient participation', 'patient involvement' and 'patient engagement', terms that are similar but should not be used interchangeably.[93] These concepts promote patient-empowerment, which is recognized as being increasingly important in the management of chronic diseases, and

which is preferred by patients with IBD.[94] Shared decision-making is also beneficial, although data on factors influencing decision-making are limited.[95]

2.7. Fistulae

N-ECCO Statement 2F

In fistulizing IBD, nurses have a role in ensuring patient comfort, protecting skin integrity, managing complications, and educating the patient about fistulae. This can best be achieved by working in collaboration with the wider MDT, including the stoma-care therapist, surgeon, gastroenterologist, and tissue viability team [EL5]. The potential psychological impacts should not be underestimated [EL2].

Fistulae may arise in CD as communicating channels between the intestine and the perianal skin, abdominal wall, or other organs.[96,97] Five aspects are important for managing 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.[20,98] Diagnostic accuracy is achieved by multiple modalities.[99]

Fistulae management remains a major challenge in patient care, and has a significant impact on HRQoL.[98] Combined medical, surgical, nursing, nutritional, radiological and other specialist interventions may be required.[100,101] Management of fistulae often requires referral to a specialist centre.[102] There is little evidence to inform nursing management of fistulizing disease, but the nurse's role may include wound care, medication administration, containment of sepsis, and support and close liaison with specialist wound-care nurses and stoma-care nurses to help enhance patient care and comfort.[103]

Surgical interventions for perianal fistulae may include abscess drainage, seton placement, and fistulotomy. In severe cases, patients refractory to medical therapy may require a diverting stoma or proctectomy.[104] Nurses need to ensure that patients are informed, and to signpost them to alternative sources of support where appropriate. Support could include enabling careful combined discussion between the patient, surgeon and specialist gastroenterologist. Referral to country-specific patient support groups, provision of information leaflets and diagrams, and in specific situations the consideration of referral for more formalized counselling to help the patient manage their symptoms and the impact on their daily living may be beneficial.[105]

2.8. Diet and nutrition

N-ECCO Statement 2G

Nurses need knowledge of the potential nutritional issues in patients with IBD in order to ensure these are appropriately identified and managed [EL2]. Patients and carers may require ongoing support and education from nurses regarding nutrition, especially in specific situations such as stricturing disease, or following surgery. Referral to a specialist dietician is recommended [EL2]. Dietary interventions may have therapeutic benefit for patients with IBD [EL1].

There is now an accepted link between the Westernized diet and the incidence of IBD.[8,106,107] Although causative mechanisms are not yet fully understood, the combination of diet and genetic predisposition towards IBD may be influential, and patients often enquire about links between diet and their IBD symptoms.[107] Patients are very interested in dietary modifications and often self-impose dietary restrictions, particularly of spicy, fatty and sugary foods, coffee, tea, carbonated drinks and alcohol, dairy products, and vegetables.[108] However there is no evidence of the benefit of dietary restrictions.

Diet is perceived to influence symptoms in CD more than in UC.[109] Patients with IBD need awareness of the importance of good nutrition for maintaining maximum health, particularly as they may lose weight during relapse, or may become deficient in nutrients, including iron, vitamin D and calcium.[110,111] Dietary advice is generally best provided by a dietician with a special interest in IBD. Freely available dietary recommendations aimed at patients are highly conflicting and tend to focus on food restrictions.[112]

IBD Nurses need to appreciate that there is no specific diet that works best for everyone with IBD,[108] and the aim is to encourage patients to follow a normal healthy diet and lifestyle as tolerated. For some patients, diet may need to be tailored based on symptoms, preferences and needs,[106,113,114] and some dietary interventions are beneficial in managing symptoms.[115] Nutrient supplements can improve nutritional status,[116,117] and exclusive enteral nutrition can induce and/or maintain remission in children and adults with IBD,[118] either alone or in combination with medications.[119]

2.9. Nutrient supplements, complementary and alternative medicines, and special diets

Access to appropriate dietary assessment and specialist advice is important, as during the course of their illness some patients may experience general malnutrition or specific deficiencies of individual nutrients. Multiple factors can lead to nutritional problems impacting on health, nutritional status and HRQoL during active disease; in addition, a wide range of nutritional and functional deficiencies can be evident after long periods of remission.[120] The most common nutritional deficiencies in IBD are of macronutrients, vitamins such as B12 and D, folic acid, and minerals such as iron, calcium, magnesium, selenium or zinc.[110,111,121] Deficiencies in serum albumin, vitamin D, vitamin B12, folate, and iron levels in patients with CD may indicate active inflammation.[122]

Vitamin D deficiency is high among patients with IBD, and may be due to sun-avoidance behaviours and reduced outdoor activity.[123] Lower levels of vitamin D correlate with increased disease activity, but a causal relationship is not clear.[124] Vitamin D has an anti-inflammatory effect and supplementation improves outcomes,[123,125,126] but the serum dose levels need ascertaining[124] and larger studies are required in this area.[127] There is convincing evidence that only those patients with CD who have an ileal resection greater than 20 cm are predisposed to vitamin D deficiency, warranting monitoring and treatment when necessary.[128] There is no evidence that supplements of the fat-soluble vitamins A, E and K are effective.[126]

The use of complementary or alternative medicines [CAMs] is common across many patient populations, and the most frequently used CAMS are probiotics, multivitamins and supplements.[129,130] Probiotics are used for pouchitis when preceded by antibiotic therapy.[112] Omega 3 fatty acids are probably ineffective in maintaining remission in CD.[131,132] There is insufficient evidence that glutamine, known to maintain the integrity of the intestinal mucosa and to reduce inflammation in experimental models, is safe and effective in inducing remission in CD.[133] Aloe vera may be effective in active

UC,[134,135] and curcumin can also be considered for induction therapy in mild to moderate UC.[132]

Special diets may or may not be effective. The low-FODMAP diet has been consistently demonstrated as reducing functional gastrointestinal symptoms [bloating, pain, gas],[136,137] and the nurse can refer to the specialist dietician if a low-FODMAP diet is considered.

2.10. Enteral nutrition as a therapy

The impact of inadequate nutrition is more noticeable in the growing child or adolescent, as nutritional deficiencies can lead to a risk of growth failure, delayed puberty, bone demineralization or significant psychosocial complications.[116,117,138] In addition, nutrition is an integral part of paediatric IBD management. The first-line treatment of choice for active paediatric CD is exclusive enteral nutrition [EEN] therapy, in which all of the patient's requirements for energy, protein and other nutrients are met by a nutritionally complete liquid diet. This EEN restores nutritional status and modulates intestinal immune responses.[139] It is an established effective induction therapy for small and large bowel disease,[118,140] inducing a response in 60–80% of cases.[118] As the first-line treatment in children with active CD, EEN is an effective alternative to pharmacological treatment, helps reverse weight loss and growth failure, and may be better tolerated than steroids. Recent evidence suggests potential benefits of EEN for adults with CD,[141,142] including inducing and maintaining remission, relieving bowel strictures and reducing post-operative septic complications in fistulizing disease.[139,142,143] Pre-operative EEN has been shown to reduce risks in urgent and planned surgery, and to decrease the incidence of post-operative complications in patients with CD.[144]

2.11. Incontinence

N-ECCO statement 2H

Nurses need to recognize the impact of incontinence on Health-Related Quality of Life. Management of faecal incontinence should be tailored to the needs of the individual. Formal referral to continence specialists for assessment and investigation may be appropriate [EL2]. Specific interventions such as providing information about pelvic floor exercises, evacuation techniques, diet, and/or continence products can be beneficial [EL1].

Faecal incontinence [FI] can be a significant problem for patients with IBD, affecting physical, psychological and social well-being and leading to symptoms of anxiety and depression.[145] The reported prevalence is 24–74%, and risk factors include disease activity, vaginal delivery, and previous IBD surgery.[37–39,146,147] There is a moderate risk of FI, particularly at night in older patients or following ileo–anal anastomosis surgery.[148] Fear of incontinence is as debilitating as its actual occurrence, and can leave patients housebound and unable to work.[36]

Often, patients find it difficult to reveal or discuss their bowel symptoms openly.[149] To properly address the issue of FI, the stigma surrounding it needs breaking down.[36,45,150] Simply by asking about symptoms, nurses can encourage patients to talk about continence issues.[151] Nurses have a vital role in helping patients to manage and improve the symptoms of FI. PROMs, such as the ICIQ-IBD,[152] which incorporates the Bristol Stool chart,[153] can facilitate accurate assessment of FI symptoms. Alongside provision of information and emotional support, specialist interventions for FI may include education about pelvic floor muscle exercises, perianal skin care, bowel retraining, anti-diarrhoeals, dietary management, behavioural therapy, and practical devices such as anal plugs and pads. Optimization of IBD treatments may also improve symptoms. There is also early evidence that electrical stimulation of the tibial nerve, a branch of the pudendal nerve supplying the pelvic floor, is beneficial.[154] However, not all patients will gain benefit from the same nursing intervention; therefore, a tailored care plan should reflect each patient's needs, taking lifestyle factors into account.[155] Specialist referral to local biofeedback or continence services, where appropriate, is recommended.

2.12. Sexuality and IBD

N-ECCO Statement 2I

Issues relating to sexuality may cause anxiety, depression and concern for patients with IBD. Nurses identifying problems regarding sexual function and sexuality need to be able to support the patient and refer them to specialist services as appropriate [EL2].

IBD commonly appears during young adulthood, and sexuality and self-confidence can be significantly affected. Sexual functioning is a marker for HRQoL, and IBD can have a meaningful impact on a person's body image, sexual functioning and interpersonal relationships.[156–158] High levels of sexual impairment have been identified among male and female patients with IBD,[159,160] but sexual difficulties need to be found to be treated.[62] Emotional aspects may include concerns about body image, feeling unattractive, and worry about urgency and leakage of stool during intercourse. The unpredictability of the disease and fear of unexpected symptoms can lead to low self-image or low self-esteem.[161]

Surgery may increase the negative impact of IBD in both males and females, particularly following proctectomy.[162,163] Decreased libido affects patients with CD and UC equally,[164] although female patients who have had surgery experience greater impairment of sexuality and sexual activity than males.[165,166]

The IBD Nurse–patient relationship can foster the confidence for sexual concerns to be raised, enabling the IBD Nurse to direct the patient towards information, to offer advice, and to identify any need for more structured support or specialist counselling. Tactful prompting and open discussion will identify the level of support needed.[167] No formal tools for measuring the impact of IBD on an individual's sexuality exist, but this may be beneficial in promoting an individualized approach to each situation.[156]

Assisting gay, lesbian, bisexual and transgender [GLBT] patients in solving problems associated with sexuality requires nurses to understand and feel comfortable discussing aspects of sexual practices of this patient group.[168] Nurses who feel under-informed can refer to the extensive literature on GLBT experiences within healthcare settings.[169,170] The GLBT patient may not wish to publicly receive emotional support from their partner during hospitalization, and may therefore avoid hospital care. Gay and bisexual patients require precise information about sexual activity and restrictions.[171]

2.13. 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 the MDT and specialist pain teams, may be able to help patients to manage this symptom. Some psychotherapeutic interventions can be helpful in managing the disease-related pain [EL2].

Abdominal pain is common in IBD and is often the first symptomatic presentation of newly diagnosed or exacerbating disease.[13,172,173] It can influence HRQoL and provoke anxiety due to its unpredictable nature, and it is often difficult to manage.[174,175] The cause of the pain may be inflammatory, such as in stricturing disease, fistulae and fissures, or non-inflammatory, such as in adhesions, fibrotic stricturing disease, or co-existing functional gastrointestinal symptoms. Extra-intestinal factors, including gallstones, renal calculi, pancreatitis, or joint/skin complications, may also cause pain.[12] Complaints of pain may trigger further investigations to uncover the cause.[172,175] A subgroup of patients will continue to experience pain without evidence of active disease on investigation.[175] In this case, the nurse needs to be empathetic and support the patient in management of their pain, which may be a manifestation of anxiety and depression or related to functional symptoms such as IBS.[172,176–178]

Fifty to seventy per cent of patients experience pain during disease flares. Pain can also be associated with, or independent of, EIMs, of which arthropathies are the most common, with a reported prevalence of up to 46%.[179] Although treatment options for abdominal pain in IBD are sparse and thus far understudied,[180] a treatment algorithm for IBD-related pain can support decision-making in clinical practice.[175]

The nurse administrating analgesics must be knowledgeable about pharmacological pain control methods, associated side effects, and drug interactions of analgesics.[172] The psychological burden of pain can be recognized and addressed, and optimizing IBD therapy may help. Opioids need to be used with caution because the use of these is complicated by dependence (when there has been chronic use) and side effects, including serious infection and mortality,[175,181] narcotic bowel syndrome (characterized by abdominal pain of unexplained nature or intensity that worsens with increased doses of opioids), and gut dysmotility.[182–184] Tricyclic anti-depressants may be useful adjuvant analgesics.[175,185] Once the cause of pain has been established, patients may be educated about this and, in conjunction with the MDT and pain management teams, empowered to recognize and proactively manage their pain, for example by taking regular analgesia.[186] The Brief Pain Inventory is a valid and reliable tool for assessment of pain intensity and interference, and effectiveness of interventions, in both UC and CD.[187] Cognitive and behavioural psychotherapy may help patients to cope with pain and improve their quality of life and functioning,[175,188,189] but it does not appear to influence the disease course in IBD.[190]

2.14. Biologic therapies

N-ECCO Statement 2K

The nurse involved in the management and delivery of biologic therapy will ensure that appropriate screening and identification of any contraindications to therapy have been undertaken and recorded. Adhering to country-specific guidelines and local protocols enhances safe administration [EL3].

Biologic therapies are a key component of medical management of IBD. Ideally, the choice of biologic [originator or biosimilar] agent should be guided by patient condition and preference after thorough discussion of efficacy and safety characteristics with the health-care professional.[94,191] However, numerous factors, including physician experience, local funding arrangements, previous response to therapies, and disease behaviour and phenotype, may override this choice.[13,191] Careful patient selection and close follow-up may decrease the side-effect burden associated with these therapies,[192] and it is vital that education regarding care and side effects is addressed prior to commencing medical therapy.[193,194] The IBD Nurse can facilitate such education and ensure information is conveyed in an uncomplicated manner.[195] Decision aids are useful when discussing adverse events, because they present evidence-based data in a pictorial form, comparing the various risks in situations that patients can easily relate to, and enhancing patient understanding.[88,196] Thorough pre-treatment screening is vital for ensuring that specific drug inclusion/exclusion criteria have been reviewed prior to administering biologics.[192] Screening includes blood monitoring, screening for active and latent infection to minimize the risk of reactivating dormant tuberculosis, radiologic screening, and risk assessment (including consideration of viral infection, immunization history and relevant co-morbidities, e.g. cardiac history, previous cancer or dyemelinating syndrome).[197] In home administration, patients need to be counselled about the risks of opportunistic infections and made aware of their responsibilities to report infections and attend for monitoring. Screening results may require onward referral to other specialists, such as for respiratory or infectious diseases. It is advisable to view the ECCO online toolkits for therapies in IBD[198] and the e-guides. Any nurse responsible for biologic therapies has to be skilled and competent in administering infusions, be aware of treatment side effects, and know how to manage infusion reactions. Nursing practice should be underpinned with evidence-based protocols for protecting the patient.[191,199,200] Checklists are a good safety measure for documenting that safe pre-treatment steps have been addressed. The expertise of the IBD Nurse can influence IBD care beyond direct patient contact, for example, by facilitating the teaching of general ward nurses to administer biologic therapies, or by developing link nursing roles.[201] Patients also need educating about self-administration of subcutaneous biologics[202]: assessment of the patient's competence and a training plan are essential and should be formally documented.

Assessment of a patient's clinical response to biologic therapies, including therapeutic monitoring for possible drug side effects, potential complications, and clinical and biochemical response, can be undertaken by the IBD Nurse, following agreed protocols, either at the time of administration or at follow-up.[203] Some centres undertake this multidisciplinary review and management of patients on biologics via virtual biologics clinics.[204,205]

2.15. Health maintenance

N-ECCO Statement 2L

Health maintenance is an integral part of routine preventative care for patients with IBD. Nurses can identify risk, screen, provide support, and refer as necessary [EL4].

Effective preventive measures for reducing morbidity, hospitalization and surgery are critical for improving disease-free remission and quality of life.[206] Patients may not access routine preventative care, mainly due to a clinical focus on IBD severity and symptom control, patient refusal to engage in prevention activities, or reimbursement issues.[206]

Health maintenance for patients with IBD includes preventing disease-related complications and disease- or treatment-related infections, and minimizing adverse effects from medications.[207] The IBD Nurse can take a thorough medical history soon after each patient's initial diagnosis, including infectious disease, vaccination and smoking history. If the vaccination history is unclear, appropriate titres can be obtained in order to revaccinate prior to commencing immunosuppressant therapy.[192] Inactivated vaccines can be safely administered to all patients with IBD, regardless of the degree of immunosuppressant.[122] Live virus and bacterial vaccinations, including BCG, are contraindicated in immunocompromised patients, and annual inactivated influenza vaccination is recommended.[208] Further information regarding vaccinations can be found in Section 4.

Smoking is associated with an increased risk of complications in CD, worsening of disease course at an earlier age, post-operative fistula formation, decreased response to medical therapy (including biologics), and increased risk of most malignancies.[209] Smoking cessation could be addressed often,[207] as patients with CD who stop smoking have fewer relapses when compared with continuing smokers.[206] Nurses should have knowledge of local smoking cessation services for supporting patients.

Patients with IBD have increased risk of developing metabolic bone disease, including osteopenia and osteoporosis, especially if previously treated with steroids; however, patients with CD are at risk for osteoporosis independent of steroid use.[207,210] Diminished absorption of vitamin D and calcium increases the risk of osteoporosis. Ideally, regular measurement of 25-OH vitamin D levels and bone-density testing could be completed in all patients with additional risk factors for osteoporosis.[210] Primary prevention of fragility fractures includes adequate vitamin D supplementation, calcium intake, and physical activity.[211] The most effective medical therapies for osteoporosis include bisphosphonates.[15]

Colon cancer surveillance is recommended every 1–5 years for patients with IBD, commencing 8 years after diagnosis, dependent on disease location. Annual colonoscopy is recommended in patients with the additional diagnosis of PSC.[12]

Women with IBD have a slightly increased risk of cervical dysplasia,[122] and young immunocompromised women should have a Papanicolaou [Pap] smear test twice in the first year of diagnosis and, if the results are normal, annual screening thereafter.[157,212] Human papillomavirus vaccination is recommended for males and females aged 9–26 years.[122,192,213]

Development of non-melanoma skin cancer is associated with use of immunomodulators, especially thiopurines, although patients with IBD have an increased risk of developing melanoma regardless of medication use.[122] Regular dermatological examination, including counselling, is recommended for all immunocompromised patients. Natural skin protection is suboptimal in patients with IBD[214]; therefore, counselling on prevention of sun exposure, wearing sun-protective clothing, using sun block and avoiding tanning beds is recommended.[122]

2.16. Fatigue

N-ECCO Statement 2M

Nurses are well placed to identify, acknowledge and provide treatment and support for patients with IBD who are experiencing fatigue. The causes of fatigue may be multifactorial, and nurses, through discussion and holistic assessment, may be able to help patients manage it [EL5]. Fatigue in IBD can be formally assessed using a validated generic or IBD-specific fatigue assessment scale, according to local availability [EL2]. A holistic approach, incorporating assessment of psychological aspects, is recommended [EL3].

Fatigue in IBD is a common complaint during relapse, and also affects over 40% of patients during remission.[215] It is widely described as 'unpleasant, unusual, abnormal or excessive whole-body tiredness that is disproportionate to or unrelated to activity or exertion and present for more than a month'.[216] Not dispelled easily by rest or sleep, fatigue can have a profound negative impact on the person's quality of life.[217,218] Its complex, invisible and changeable nature can make it difficult for patients to describe the experience of fatigue to others,[51,219] and fatigue is often poorly understood by health-care professionals, who may underestimate the impact on the patient.[220]

The aetiology of fatigue can be multifactorial, and there may be a genetic predisposition.[221] Physical assessment, and biochemical and haematological testing may provide explanations. Persistently low iron stores, low haemoglobin, or raised inflammatory markers in the absence of bowel symptoms, are examples of reversible causes of fatigue. Low serum levels of vitamin D, IGF-1 and magnesium have also been linked to muscle fatigue, correlating well with self-reported fatigue, in patients with CD.[222] IBD Nurses can monitor this and provide advice on management. An early review suggested that one-third of patients with IBD suffer from recurrent anaemia, which may contribute significantly to fatigue. Active identification and treatment of anaemia was recommended.[223] Conversely, two studies have reported no correlation between anaemia and/or iron deficiency.[224,225] However, fatigue appears to be most marked for female patients[224,225] and those less than 60 years old,[225] and thus may have a greater impact on those with families, and those of school and working age.[226] In addition, co-morbidity, a low level of education, and being unemployed may influence the perception of fatigue in IBD.[227]

A holistic assessment is necessary in order to identify physiological, psychological and any other potential causes of fatigue.

Psychiatric conditions can co-exist with physical illness, and evidence supports this relationship in IBD, with the prevalence of mood disorders such as anxiety and/or depression possibly up to three times greater than in the general population.[176,228] Fatigue is associated with increased levels of disease-related worries and concerns in IBD, which in turn are associated with impaired HRQoL.[226,228] Sleep quality and psychological factors (such as anxiety, depression, disease-related worries, co-existing IBS and perceived disease activity) have consistently been identified as being strongly associated with fatigue in both patients with UC and patients with CD.[226,229–235] Fatigue is reported as being more severe in patients with CD[230,233] and in newly diagnosed patients, independent of disease activity.[229,236]

Once fatigue has been identified, the IBD Nurse can monitor the patient to determine any improvement or worsening of fatigue symptoms. Optimization of medical management is likely to alleviate fatigue in patients with UC over time,[237] and once biochemical, haematological or endocrine causes have been excluded, the nurse can work with the patient to identify strategies and coping mechanisms that may help manage fatigue. Strategies could include 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.[238,239] In the absence of physiological causes of fatigue, moderate activity and psychological interventions, particularly exercise and solution-focused therapy, appear to be the most promising interventions,[237,238] but more research is needed.[240,241] Patients may need encouragement to report fatigue to and seek help from health professionals,[242] and some may be reluctant to discuss fatigue if they perceive that no cure is available for it.[243]

3. Advanced IBD nursing

3.1. Definition, requirements and skills

In this document, the term 'Advanced IBD Nurse' refers to an experienced adult or paediatric nurse caring for people with IBD at an advanced level attained by extensive clinical practice, professional development, formal education and the application of research skills.[244,245]

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 practice within their own professional competency and accountability, supported by protocols or guidelines in collaboration with the MDT [EL5].

The Advanced IBD Nurse is often referred to as a clinical nurse specialist, advanced practitioner, or consultant, who works autonomously in collaboration with the MDT and the patient. The Advanced IBD Nurse plays an important role in assessment, diagnosis, treatment planning, evaluation, monitoring, surveillance, education, health promotion and practical and emotional support for a caseload of patients with IBD, within the scope of their own professional practice and limitations.[246] The Advanced Nurse will work within local, national or international guidance or protocols. Although the specifics of the role will vary depending on national and local needs, the international literature suggests commonalities in the expected skills required for advanced practice. These include: competencies in advanced clinical skills, which may include physical assessment, performing and interpreting endoscopy, or prescribing; 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.[245,247–250]

3.2. The Advanced IBD Nurse's role

N-ECCO Statement 3B

The Advanced IBD Nurse works as part of the IBD MDT, enhancing patient care and experience, and providing efficient, holistic and accessible care [EL 5]. The Advanced IBD Nurse's role additionally 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 post-graduate education [EL5].

Although the largest proportion of the Advanced Nurse's time is spent in direct clinical practice, other activities such as education, research, leadership and service development are essential role components.[245,246,248,250,251] There is no consensus on the expected level of education, which varies between countries and organizations and may be governed by national professional standards and regulatory requirements.244 It is generally agreed that Advanced Nurses should have a first degree at minimum, though many will be educated to Masters or Doctorate level. Although research remains a recommended core activity of the Advanced Nurse role, little time is dedicated to research, compared with the time dedicated to clinical care.[245,251–254] Advanced IBD Nurses are well placed to undertake research and to explore areas that impact on the patient's quality of life and psychological health, effects on family, employment and education, and financial implications of disease, all of which are areas of concern for patients. 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, and that nurses are supported in attaining the skills or confidence they often feel they lack for conducting research.[255]

Leadership is pivotal in effecting change in clinical practice, and enhanced leadership skills can improve team effectiveness and lead to provision of more patient-centred care.[256] Components of effective leadership include practice leadership, role modelling, promoting patient safety, caseload management, evaluation of services or interventions, facilitating improvements or innovations, consultancy, being able to develop self and others, and change management.[245,257] Leadership may be demonstrated through problem-solving, critical thinking, listening, and engagement with the MDT team or stakeholders.[245] Networking and sharing of practice via national and international groups is an important aspect of leadership. N-ECCO is one international nursing network that enables practice development and best practice across several countries to be shared.

Locally, each hospital is 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 of achieving the necessary advanced skills.[247,250,253,258] Policies, protocols and guidelines are useful frameworks for supporting the clinical activities of the Advanced IBD Nurse. However, Advanced IBD Nurses also work beyond protocol-led care, with freedom to use their clinical acumen, while acknowledging professional limitations, and seeking advice where appropriate.

3.3. The Advanced IBD Nurse's role in the planned review, care and follow-up of stable patients

N-ECCO Statement 3C

The Advanced IBD Nurse can conduct regular patient reviews face to face, via telephone or electronically in order to monitor treatments, and arrange appropriate investigations as required, in accordance with local policy or guidance [EL5]. The limitations of remote contact must be considered and skilled judgement used in knowing when further assessment is required [EL5].

Patients with IBD require long-term outpatient follow-up and surveillance. Disease activity often fluctuates over time, requiring maintenance therapy and acute interventions for disease flares. Complex disease management requires a specialized MDT approach that enhances the level of continuous care and improves outcomes. In this dedicated team, a key role for the Advanced IBD Nurse is increasingly being recognized.[259] Advanced IBD Nurses are consistent team members who work with patients over a period of time. This continuity is one of the advantages, over other groups of health-care professionals, of Advanced IBD Nurses' involvement in follow-up.[260,261]

Advanced IBD Nurses facilitate the follow-up of patients during relapse and in remission, providing a link between the patient and the family doctor and hospital care, and rapid access in the event of a flare up.[262,263] The Advanced IBD Nurse, who reviews patients independently of medical colleagues, has the added responsibilities of raising any issues of concern that fall beyond their scope of practice with appropriate medical colleagues, and of being aware when onward referral is necessary. Patients receiving conservative management in specialist nurse services report high levels of satisfaction, improved ability to live with symptoms and a better quality of life .[264] Nurse-led clinics have been shown to almost halve the number of physician visits, thus reducing the medical workload in IBD units.[265]

3.4. The Advanced IBD Nurse caring for complex patients

N-ECCO Statement 3D

The Advanced IBD Nurse plays a key role in the IBD MDT when caring for complex patients, and will be able to assess the patient's care needs and refer them on, if needed [EL5].

Advanced IBD Nurses have a pivotal role within the IBD MDT because they can provide direct care as well as holistic support[266,267] and make a significant contribution to patient experience, including facilitating complex decision-making regarding patient care. The Advanced IBD Nurse develops the role of providing social, physical and psychological support in addition to providing education and promoting understanding for the patient and their family when IBD becomes complex. Further, the Advanced IBD Nurse plays a key liaison role, acting as the patient's advocate at IBD MDT meetings and ensuring there is focus on managing IBD in the context of the patient's life, rather than just in terms of disease activity.[88]

The changing demands of IBD in terms of complex treatment algorithms, place the Advanced IBD Nurse at the centre of care to ensure that the patient's needs are met through ongoing delivery of high-quality evidence-based care.

3.5. The Advanced IBD Nursing assessment

N-ECCO Statement 3E

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, provided appropriate training has been undertaken. The Advanced IBD Nurse will be aware of existing assessment tools that may be useful aids in the management of patients with IBD and their related health problems [EL5].

To develop a care plan for any patient in any situation, whether face to face in the clinic, or via telephone or email, a thorough, competent and relevant assessment is vital.[246,251,268,269] At the first meeting, a comprehensive 'IBD history' may be recorded, including age at diagnosis, extent and duration of disease, any history of surgical procedures, current and past medications, any drug side effects or intolerances, and dietary triggers or intolerances. It is also important to gauge the patient's understanding of IBD, its management, and the care they are receiving. Assessment proformas are a useful tool for ensuring a consistent approach, and can be used by nurses at various levels.[269] Assessment of current disease activity, including EIMs, dietary history, HRQoL, coping strategies, psychological well-being, social support, and health behaviours (e.g. smoking, and drug adherence) can be reviewed. Confirmation of medication used, including complementary and alternative medicines [CAMs] and over-the-counter preparations, as well as response to or adverse effects of prescribed treatment, is an important aspect. Fever, nausea, vomiting, weight loss, fatigue or other signs indicative of active disease can be identified. Validated disease activity scoring systems, such as The Harvey–Bradshaw Index [HBI] for CD, or the Simple Clinical Colitis Activity Index [SCCAI] for UC,[153,270,271] aid consistent assessment of disease severity, enable objective measurement of improvement or deterioration in the patient's condition, allow for revision of the treatment plan, and support audit and research.

The Advanced IBD Nurse may use other assessment methods such as abdominal examination, interpretation of endoscopy, blood tests, faecal calprotectin, radiology, histology and other imaging tests, all according to training, skills and local protocol.[272] Objective measures such as the Inflammatory Bowel Disease Questionnaire [IBDQ] or the Hospital Anxiety and Depression Scale [HADS] are useful for assessing HRQoL and psychological well-being.[273,274] Other scoring tools, such as pain or fatigue scores, may be appropriate in certain situations.

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 with the general population, but have enhanced social support.[275–277] The Advanced IBD Nurse can assess the social impact and the patient's existing resources both within the family and wider social structure. It is useful for the Advanced IBD Nurse to have some knowledge regarding national employment laws for people with a chronic disease, and to refer the patient for additional support, such as country-specific patient support groups and charities, if needed. Completing a thorough holistic assessment enables the Advanced IBD Nurse to implement appropriate plans of care and to identify other direct and indirect effects such as psychological morbidity, presence of functional gastrointestinal disorders, incontinence, fatigue, anaemia, and problems with sexuality, fertility, drug monitoring and compliance.[278]

3.6. The Advanced IBD Nursing role in managing Advice Lines

N-ECCO Statement 3F

Advice Lines are considered a key element of an Advanced IBD Nursing role and may improve clinical and service outcomes [EL5]. This type of contact provides rapid access to a specialist nurse. It is suitable for providing many aspects of care, information and support, and for the assessment, investigation and treatment of the unwell patient [EL3].

From the patient perspective, rapid and direct access to an IBD Nurse is of great importance.[261,279] An IBD service including advice lines [ALs] has been identified as an element of 'best practice' in an observational study in eight European countries.[280]

Besides the direct effects of IBD, patients may experience other life challenges as a consequence of their condition. Issues around schooling, employment, smoking, diet, pain, fertility and pregnancy, travel, sexual and other relationships, adherence, stigma, transition from childhood to adulthood, fatigue and more may be addressed via a telephone or email AL.[281–284]

ALs managed by IBD Nurses are safe and cost-effective. ALs can reduce out-patient visits and help avoid inpatient stays.[285–288] Furthermore, ALs can reduce the need for some face-to-face reviews, but may also, wrongly, be perceived as a means of keeping patients away from outpatient clinics.[289] ALs provide prompt and appropriate expert nursing advice, and access to clinics and to consultant support when the need is urgent. Advanced communication skills must be utilized, especially when using remote assessment, as non-verbal cues cannot be used. Appropriate levels of practitioner competency and knowledge are emphasized.[290] Protocols may enable the development of agreed expectations of an AL service.[280] Local protocols will reflect local practicalities and legalities and outline the aim, responsibility, and the remit agreed for those involved in running an AL.[287,291]

3.7. Patient information and education

N-ECCO Statement 3G

The Advanced IBD Nurse assesses understanding and, informed by current evidence, provides education to patients with IBD and their significant others based on individual needs, preferences and coping ability, aiming to empower the patient to live well with IBD. The Advanced IBD Nurse can direct the patient toward trusted sources of educational materials [EL5].

The Advanced IBD Nurse can be perceptive to the patient's educational needs and provide essential information and education for patients, which may take various forms e.g. group, individual or family focused.[292] Patient education may need to be repeated and supported by other avenues e.g. phone, written information, electronic means, and country-specific patient support groups.

A wide range of information and videos about IBD, of variable quality, are available on the internet, and should only be used as supplemental information to more individualized education.[293–295] The Advanced IBD Nurse need to be able to identify, analyse and classify relevant literature and information to guide the patient.

Studies of structured patient education programmes have, to some extent, shown an increase in participants' level of knowledge and empowerment,[296] but no significant effect on HRQoL.[297–300] Since some patients choose not to participate in structured patient education, a broad range of tailored alternatives has to be available.[301]

There is no clear evidence that self-management programmes for patients with UC either improve health or increase well-being,[302] but despite this, IBD Nurses are encouraged to facilitate self-management.[303] There may be reduced economic cost for patients allocated to self-management compared with usual treatment.[304] Education towards self-management complements traditional patient education in supporting patients to live the best possible quality of life with their condition. As well as teaching problem-solving skills, a central concept in self-management is self-efficacy—confidence for carrying out the behaviour necessary to reach a desired goal.[305]

IBD teams are encouraged to support country-specific patient support groups and the educational and open forum sessions offered by the various charities, allowing patients to become more involved in shaping local services.[199] This also improves patients' knowledge of IBD, which in turn is associated with improved coping and adherence to treatment.[299,306] Recently diagnosed patients primarily glean information from the doctor and the internet, but two-thirds of the patients prefer information from a nurse specialist.[307] For patients with special needs, e.g. medical, cultural, mental or social; the Advanced IBD Nurse plays a key role in linking them to appropriate services in the MDT.

3.8. E-health nursing

N-ECCO Statement 3H

The Advanced IBD Nurse, along with the IBD MDT, plays a key role in the development, introduction, delivery, monitoring and evaluation of electronic health technologies [EL5].

Few studies have explored the various e-health interventions in IBD. Most had an observational design, but a small number were RCTs, including one that revealed the significant beneficial effects of a telemedicine system in visits to and contact with health-care services.[308]

Three systematic reviews revealed that e-health interventions were safe and effective for the subgroup of patients studied.[309–311] In general, study interventions and outcomes were heterogeneous, and interventions ranged from ALs and virtual clinics to smart-phone applications. The study participants were mainly patients with quiescent disease. Although it was not always clearly described, IBD Nurses appeared to play a key role in reviewing patient-reported data and in taking action as necessary.[312–314] Patients with IBD have a positive attitude towards e-health and self-management approaches as long as they are well, but rapid and easy access to both gastroenterologists and IBD Nurses remain an important supplement.[261,312] Advanced IBD Nurses naturally become involved in the implementation and operation of most e-health initiatives, and may be involved in e-health projects. Their routine and frequent use of PROMs, well-developed communication skills and competencies are essential when establishing and maintaining any remote IBD service.

4. Advanced IBD nursing care for particular situations

4.1. The Advanced IBD Nurse's role in transitional care

N-ECCO Statement 4A

The adolescent and young person with IBD needs a structured transition programme when transferring from paediatric to adult care [EL2]. The model of transition may vary according to local arrangements [EL5]. The Advanced IBD Nurse is pivotal in the transition process by liaising with the adult and paediatric MDT to ensure a flexible and individualized transition process with the patient at the centre [EL3].

Transition is described as the purposeful and planned movement of care from a paediatric- to an adult-orientated health-care service for young adults with chronic medical conditions, and the handover of health responsibility from parent to adolescent.[315] Transition differs from transfer in that transition is structured, planned and considered.[316] Effective transition programmes empower young adults to take responsibility for, and manage their own health, by equipping them with the required knowledge and skills, underpinned by appropriate health-care support. Transition programmes yield significant improvements in disease outcomes and HRQoL.[317,318]

Differing models of transition have been described, which vary dependent upon geographical area, access to public health care, and the health-care model employed. However, the importance of effective transition for any adolescent with chronic illness, and of the role of a care coordinator in improving patient outcomes within this vulnerable group, has been described in the international literature[319] and is supported by international IBD guidelines.[320–322] The Advanced IBD Nurse is well placed to undertake the key role of coordinator[320] with responsibility for transition.[317,323] International audits have identified that, alongside other clinical benefits, the services provided by an IBD Nurse within the MDT are associated with successful transition of adolescents from paediatric to adult-orientated IBD services.[323,324]

4.2. IBD and travel

N-ECCO Statement 4B

Whenever necessary, the patient with IBD planning to travel receives appropriate pre-travel consultation and education regarding the risks and practical issues of travel with IBD. The Advanced IBD Nurse can be a source of information, support and referral to relevant resources. Special consideration should be given to patients on immunosuppressants [EL4].

4.2.1. Pre-travel consultation

Foreign travel is associated with an increased risk of travel-related morbidity caused through exacerbations of IBD, acquisition of infectious diseases endemic to the destination, and less availability of health care and medicines while abroad.[325,326] Patients receiving immunosuppressive medication, such as azathioprine, methotrexate and 6-mercaptopurine, have increased susceptibility to these infections, in addition to an attenuated immune response to vaccinations.[325,327–330] Detailed pre-travel consultations and vaccinations are advised in order to ensure travellers have the appropriate education and resources to stay healthy during their journey.[325,330–332]

Pre-travel preparation and education among patients is poor, with many failing to obtain any formal pre-travel advice, having inadequate travel insurance to cover IBD, and lacking awareness regarding vaccinations.[326,333–335] Health-care professionals' knowledge and provision of pre-travel counselling and adherence to international guidelines is also poor,[336,337] particularly regarding avoidance of live vaccines for those on immunosuppressive medication.[338–340]

The pre-travel consultation may be an MDT approach involving the Advanced IBD Nurse, gastroenterologist, family doctor, travel clinic and, for complex patients, the infectious diseases team. The consultation involves support and encouragement for travel—IBD need not restrict patients from foreign travel—and signposting to IBD-specific travel experts and resources.[340] The Advanced IBD Nurse can be involved in the discussion regarding travel destination and related level of risk, particularly for those on immunomodulator therapy, including the importance of obtaining travel insurance to cover IBD, and food and water precautions for avoiding travellers' diarrhoea.

4.2.2. Vaccination advice

Administration of live vaccines to patients on immunosuppressant medication, such as azathioprine, 6-mercaptopurine and methotrexate, is contraindicated. Serious and potentially fatal infections can arise due to extensive replication of the vaccine strain, which does not happen with inactivated vaccines. Some vaccinations for travel such as yellow fever, typhoid and BCG are only available in a 'live form'. It is recommended to use a standardized checklist for immunization against opportunistic infections.[325] Good communication between the IBD MDT, travel clinics and patient is therefore essential for ensuring safe vaccination and travel. The ECCO 'evidence-based Consensus on the prevention, diagnosis and management of opportunistic infections in inflammatory bowel disease' details individual vaccinations required prior to commencing and discontinuation of immunosuppressant therapy, for example, varicella vaccine must be administered 3 weeks prior to starting treatment, and subsequent immunization can only be administered after 3–6 months after discontinuation.[192]

4.3. Pregnancy and fertility

N-ECCO Statement 4C

The Advanced IBD Nurse plays a pivotal role in supporting the patient who is considering pregnancy. Pre-conception counselling addressing fertility and pregnancy outcomes would ideally start as early as possible with both males and females in order to support decision-making [EL5]. Controlling active disease prior to and during pregnancy is important [EL3, EL5].

Reproduction and pregnancy in patients with IBD are described in the ECCO guidelines.[157]

4.3.1. Fertility

Compared with an age-matched population, female patients with quiescent IBD do not have decreased fertility. Low birth rates among woman with IBD are often due to personal choice rather than disease-related infertility.[341–344] The knowledge of women with IBD regarding pregnancy is often poor,[345,346] requiring assessment by the Advanced IBD Nurse and provision of appropriate disease-related education.

Women with active disease may experience subfertility and problems achieving pregnancy.[347] IBD-related complications such as abscesses and fistulae in the genital region may result in sexual abstinence. Restorative proctocolectomy with ileoanal anastomosis has been associated with reduced sexual activity due to scarring and formation of adnexal adhesions.[343,348,349]

There is no reported evidence of medications affecting female fertility.[157] Male fertility may be decreased by methotrexate (which is teratogenic) and sulfasalazine (which can cause oligospermia, reduced sperm motility and abnormal sperm morphology),[350–353] although these effects are fully reversible within a few weeks of stopping the drug. Subfertility in male patients may also be related to poor nutrition, depression and reduced libido.[347] Proctocolectomy in men may lead to impotence or ejaculatory difficulties.[354]

4.3.2. Preconception care

Preconception counselling is recommended because women with IBD who conceive while in remission are more likely to remain in remission during the course of their pregnancy, although women with UC have more disease activity during pregnancy than those with CD.[354]

Family-planning and breastfeeding issues could be discussed with both males and females before treatment, because some patients may wish to stop treatment before conception.[355] The Advanced IBD Nurse may address specific patient concerns in order to optimize control of disease, avoid inappropriate medication cessation, and discontinue medications that may adversely affect pregnancy. Patients often have concerns about IBD inheritability, the risk of congenital abnormality, and medication teratogenicity.[342,356] To provide optimal evaluation and treatment, the Advanced IBD Nurse as well as the IBD MDT needs to be aware of the diverse spectrum of conditions and problems that may be encountered.

4.3.3. Pregnancy and post-partum care

N-ECCO Statement 4D

An MDT approach is recommended as appropriate [EL3, EL5]. The Advanced IBD Nurse can be a source of support and education during the pregnancy and post-partum period, in particular, regarding breast feeding and medication safety [EL5].

The severity and extent of disease at conception appears to influence the course of disease during pregnancy; approximately two-thirds of woman in remission will stay in remission, while active disease at conception is likely to persist and possibly worsen in two-thirds of women during pregnancy.[157]

Disease activity is the main adverse factor predisposing to intrauterine death, prematurity and low-birth-weight babies.[357,358] The balance between maintaining or discontinuing IBD treatment, which increases the risk of an acute exacerbation requiring prompt treatment,[157] needs to be weighed up for each individual. Women with IBD often overestimate the harmful effects of medication, while underestimating the harmful effects of an IBD flare during pregnancy.[356,358,359] Continued drug therapy may be necessary and the patient may need to be counselled about the risks of discontinuing medication.[360]

If pregnant women require hospitalization for IBD, they may be transferred to a tertiary centre with an MDT.[356,359,361–364] Labour and delivery plans should be discussed between the gastroenterologist, obstetrician and patient. The choice of vaginal or caesarean delivery may be influenced by IBD and/or disease activity and patient choice.[157] Breastfeeding is strongly encouraged due to the reported benefits for both mother and child. Breastfeeding does not increase the risk of disease flare and may even provide protection against flare in the post-partum year.[365,366] The Advanced IBD Nurse can play a pivotal role throughout the woman's pregnancy, providing advice on the safety of medicines while breastfeeding, and offering timely reviews to minimize the risk of relapse.[367]

4.4. The Advanced IBD Nurse's role in IBD iron deficiency and anaemia

N-ECCO Statement 4E

The Advanced IBD Nurse is well placed to identify iron deficiency anaemia, and to facilitate iron supplementation in patients with IBD, monitoring both effects and side effects of treatment [EL5].

Anaemia is a common EIM in IBD, and prevalence depends on disease activity. Approximately 25% of patients will have anaemia, although prevalence has been reported at 50% among IBD outpatients observed over a 2-year period.[368] Prevalence is slightly higher in patients with CD than in patients with UC.[369] Anaemia is considered present if haemoglobin levels are <12 g/dL in non-pregnant women and <13 g/dL in men.[370] The detection, treatment and monitoring of anaemia and iron deficiency are described in the ECCO guidelines.[371]

The main causes of anaemia in IBD are inflammation and/or iron deficiency. Anaemia of chronic disease [ACD] is caused by inhibited bone marrow activity and reduced iron uptake due to inflammation.[371] Iron deficiency anaemia [IDA] in patients with IBD may be caused by a combination of blood loss from the bowel, malnutrition with reduced iron intake, or impaired iron uptake.[368] The Advanced IBD Nurse investigates and interprets results to identify IDA and ACD and their consequences, and provides treatment as appropriate. This includes oral iron, IV iron therapy (with monitoring for effects, side effects and adherence to treatment) and referral to dieticians or gastroenterologists as required.

4.5. Caring for the patient undergoing stoma and ileal–anal pouch formation

N-ECCO Statement 4F

The Advanced IBD Nurse is well placed to support the patient in the peri-operative period by being a source of education and referring to appropriate members of the MDT, particularly the stoma nurse. Psychologists, sexual therapists and country-specific patient organizations can help with information provision and psychological support [EL5].

Many patients are understandably distressed at the thought of undergoing either planned or emergency surgery, and the Advanced IBD Nurse plays a key role in coordinating health-care professionals. Patients may undergo a colonic resection without stoma formation, or require further surgery to include restorative proctocolectomy with ileal pouch–anal anastomosis [IPAA]. The main indication for IPAA is in patients with medically refractory UC,[372,373] or dysplasia or cancer developed from underlying UC.

For any complex surgical procedure, the patient is best managed within an MDT including the Stoma Care Nurse. In the event of stoma formation, the Stoma Care Nurse provides essential support and education for the patient and their family prior to surgery, during the hospital stay and following discharge.[374]

Stoma and IPAA surgery provide numerous benefits, including long-term symptom relief,[372,375] although recent evidence suggests that while outcomes are often better than anticipated, some patients require a long time to decide about stoma surgery and find benefit from pre-operative contact with another patient with IBD living well with a stoma.[29]

4.5.1. Caring for the patient with an ileoanal pouch

N-ECCO Statement 4G

The Advanced IBD Nurse is well placed to identify problems associated with pouch function (including pouchitis and dysfunction) and quality of life, fertility and pregnancy, incontinence, and sexual issues. The Advanced IBD Nurse can support the patient and provide education and information regarding the pouch, referring on as appropriate [EL5].

Pouch dysfunction can occur following surgery and can be caused by pouchitis, cuffitis, irritable pouch syndrome, CD, or pouch fistula. Pouch failure requiring surgery and removal of pouch can sometimes occur,[372] and diagnosis depends on endoscopic and histological findings in conjunction with symptoms.[376]

Approximately 25% of patients will develop recurrent pouchitis, with 5% enduring chronic pouchitis requiring maintenance therapy or, on rare occasion, pouch excision.[372] Factors associated with an increased risk of pouchitis include PSC, EIMs, and non-smoking status. Controversy surrounds other risk factors such as extent of colitis and backwash ileitis. The etiology of pouchitis is unknown, but theories range from genetic susceptibility, bacterial overgrowth, ischaemia, and faecal stasis, to a recurrence of UC in the pouch, a missed diagnosis of CD, or possibly a novel third form of IBD.[372] Some patients with symptoms of pouchitis will not have inflammation, but rather, irritable pouch syndrome.[372] Symptoms related to pouchitis include increased stool frequency and liquidity, abdominal cramping, urgency, tenesmus, and pelvic discomfort. Fever, EIMs and rectal bleeding may also occur, although the latter is more often related to inflammation of the rectal cuff than to pouchitis.[373,377] Faecal incontinence may occur after IPAA without pouchitis, but is more common in patients with pouchitis.[372] The Advanced IBD Nurse, other members of the MDT and the stoma/pouch care nurses provide support for the patient if complications develop, and if the pouch needs to be removed.

4.6. IBD in elderly patients

N-ECCO Statement 4H

The Advanced IBD Nurse is in a position to assess the health risks or frailty of elderly patients with IBD regarding medication [polypharmacy], medical history, co-morbidities, bone density, incontinence, cognitive deficit, and depression [EL5].

Care of the elderly patient with IBD is extensively covered in the ECCO topical review.[378] A key characteristic of the health status of the elderly is its large heterogeneity in terms of the effects of ageing on individuals' quality of life, functional limitation, and the type of diseases and conditions affecting them.

Until recently, little data existed about IBD in the older person. Possible explanations for this include higher rates of exclusion from clinical trials (primarily due to concerns about ageing itself increasing the risk of adverse events) and less endoscopic procedures being performed within this population.[379]

Approximately 25–35% of people living with IBD are elderly, with 15% of those being diagnosed 'de novo' with conditions in later life. Incidence rates of UC are currently greater than for CD in the older person, but increased rates are anticipated in both disease groups.[379,380] Effects of ageing include frailty, degeneration, reduced recovery capacity, co-morbidity, polypharmacy, and shortened life expectancy.[379] The older person with IBD can be stratified into one of two subgroups: elderly onset IBD and elderly IBD patient. 'Elderly Onset IBD' is defined as the first presentation/diagnosis of IBD in an individual aged 60 years and over, while an 'Elderly IBD Patient' is an individual aged 60 years or over with an established IBD diagnosis. Ageing with a known diagnosis of IBD may increase the risk of complications and prolonged hospitalization, and may be associated with higher incidences of morbidity and mortality.[379–381]

When making management decisions for care of the elderly with IBD, the Advanced IBD Nurse needs to assess the patient's frailty and acknowledge the difference between the chronological and biological age.[382] Validated measures of frailty may be used.[383]

4.6.1. Health risks in the elderly with IBD

The principles of medical management for elderly individuals with IBD are the same as for any adult patient: to induce and maintain remission of symptoms, promote quality of life, and prevent complications of disease. However, advancing age can bring specific challenges, including depression.[384–386] The Advanced IBD Nurse requires an understanding of elderly patients' needs, including their social history and support network, in order to identify when intervention and referral to outside agencies such as social care is required.

From 26 to 48% of patients with IBD have decreased bone density and a 40% higher risk of fracture, compared with the non-IBD population. Older age is also a risk factor for development of osteoporosis. However, establishing the degree of bone loss due to ageing is difficult in patients with IBD due to confounding factors of corticosteroids use, poor nutrition, duration of disease and ongoing active inflammation, and body habitus.[384,387–389]

An elderly patient with at least two chronic diseases will usually exceed the arbitrary threshold of more than five medications. The consequences of polypharmacy include greater health-care cost, increased risk of adverse drugs events, drug interactions, medication non-adherence, reduced functional capacity and multiple age-related syndromes. Polypharmacy may be more common in elderly patients with IBD, and the potential for drug interactions must be considered. Problems with administration (e.g. of rectal therapies) merit careful consideration by the Advanced IBD Nurse.[390–392]

5. Benefits of an IBD Nurse

N-ECCO Statement 5A

The Advanced IBD Nurse provides a pivotal and important role in the care of patients with IBD, within the IBD MDT and to health-care providers. Nurse-led services, including telephone ALs and out-patient clinics, have been demonstrated to be cost-effective and beneficial to patients and health-care providers [EL3].

Although generally accepted as beneficial to patients and services, a key challenge for the Advanced IBD Nursing role since its inception has been to demonstrate this benefit. This specialist nursing role was the first to be reviewed for the Cochrane database[393]; however, reviewed studies were assessed as having low methodical quality, resulting in benefits being difficult to quantify. ECCO, N-ECCO and the N-ECCO Research Forum continue to work to improve the quality and transferability of research into the Advanced IBD Nurse role.

5.1. Organizational benefits

A number of organizational benefits of the Advanced IBD Nurse role have been demonstrated, including greater integration of care across MDTs,[394] and the bridging of primary and secondary care interfaces. As discussed in Section 3, Advanced IBD Nurses play a vital role within the IBD MDT.[88,395–398] Patients report greater satisfaction of care with an IBD Nurse in the team,[399] with improved access to better coordinated care, and better education and support for them and their families/carers.[395] In the UK, centres with an Advanced IBD Nurse in the MDT have fewer hospital admissions, provide access to self-management approaches for disease control, and give greater choice regarding delivery of follow-up care for patients.[261] One Austrian IBD service (consisting of a gastroenterologist, an IBD Nurse, a weekly designated IBD clinic, a joint medical–surgical clinic for IBD, and a regular time for radiology review) was developed and coordinated by the Advanced IBD Nurse. Health-care utilization, number of admissions, and disease burden decreased significantly, demonstrating financial and clinical gains for patients.[400] Benefits have also been demonstrated in transition services in which the skill of the Advanced IBD Nurse can facilitate adjustment to the many demands faced by the young person with IBD and their family as they progress to adult IBD services.[397,401–404]

As discussed in Section 2, IBD Nurses at any grade may be involved in delivering biologic therapies, but the service delivery of this treatment modality is now routinely managed in many centres by the Advanced IBD Nurse.[191,397,398] One UK audit found that 90% of IBD Nurses had direct clinical responsibility for delivering biologic services within their institution,[405] a role that incorporates patient counselling, safety pre-treatment screening, and delivery of therapy. The Advanced IBD Nurse is influential in improving quality of life outcomes in patients through increased safety monitoring.[406,407] Monitoring for side effects and adverse blood results is described as vital 'rescue work',[408] and is essential for patients on immunosuppressive therapy to minimize potentially serious adverse events such as neutropenia or myelotoxicity, and reduce the burden of disease severity and activity. Recent advances with therapeutic drug monitoring, including measurement of trough levels of drug and antibody detection, further underpins the need for Advanced IBD Nurses. 'Virtual' review of patients receiving biologic therapies provides a more cohesive monitoring model with ease of two-way feedback for patient and clinician, helping to ensure the most benefit for patient and cost-effectiveness is obtained from therapy.[205,398] The Advanced IBD Nurse will often oversee this review, ensuring relevant clinical information and patient outcomes are reported appropriately. Despite this, many IBD centres across Europe delivering biologic services still do not have access to an Advanced IBD Nurse as part of the MDT. In 2013, a quarter of UK hospitals still had no IBD Nurse,[409] and a 2016 Italian audit revealed that less than 40% of centres treating patients with biologic therapy had access to a specialist IBD Nurse,[266] highlighting the need for continued work and investment in this area.

5.2. Better access to care, reduced waiting times, and cost benefits arising from an IBD Nursing service

Patients describe the IBD Nurse as a constant and reliable source of contact, providing immediate advice.[285,393,395,410] Prompt access is the most frequently cited benefit of an IBD nursing service from the patient perspective. Increased access to the IBD team, via telephone ALs managed by Advanced IBD Nurses, has also been demonstrated to significantly reduce costs associated with unscheduled primary and secondary health-care visits.[259,285,410] High levels of patient contact episodes are recorded via helpline services across Europe.[285,411] Where a monetary tariff can be attached, ALs generate income for the IBD service.[285,288,412] Studies demonstrate that outpatient visits and hospital admissions can be avoided through counselling by phone or email with the IBD Nurse.[73,259,288] AL services enable Advanced IBD Nurses to conduct 'rescue work'[408] and facilitate faster access to procedures and other relevant departments.[259,288]

Patients with quiescent disease can often be managed by IBD Nurse–led telephone clinics, with proven cost-effectiveness and acceptability to patients and health-care providers.[413–416] The Advanced IBD Nurse's enhanced knowledge ensures assessment of patients' immediate needs, skilled decision-making and care planning, and access to the safety net of MDT care services when nee ded.[393,411,417,418] Length of hospital stay may also be reduced by IBD Nurse–led follow-up, thereby improving patient satisfaction overall.[260,285,412,419] Balancing the delivery of safe and effective care in addition to managing cost savings, while challenging, is enhanced by the expertise of the IBD nursing team.[400] While the initial costs of employing an IBD Nurse are recognized to be high, the overall savings are undisputed in centres that employ IBD Nurses.[400]

5.3. The benefit of the IBD Nurse for patient health-related quality of life and self-care

The burden of disease for patients with IBD extends beyond the costs associated with their clinical care, investigations and treatments.[420] IBD often causes considerable social encumbrance, mainly due to the bowel-related symptoms. Despite more liberal attitudes towards, for example, sexual function, bowels remain taboo. Patients can find it extremely difficult to talk about and seek support for their problems, despite the negative impact symptoms may have on educational and career aspirations, and on relationships and social activity generally.

Whether face to face or via the AL, the Advanced IBD Nurse acts as a valuable resource for patients, enabling them to learn more about their disease, thus increasing confidence and subsequent disease-management ability, and directly benefitting their overall quality of life.[262,421–424] Advanced IBD Nurses can also provide ongoing support to family and carers who may be affected by the repercussions of the disease and therefore require information, support and advice to manage concerns on a daily basis.[393]

It is crucial for successful treatment that patients acquire insight into their disease, and understand the importance of adhering to the recommended maintenance treatment regime. Despite non-adherence being a major risk factor for experiencing a relapse and increasing the risk of acute hospitalization and surgery, both adult and paediatric patients often fail to adhere to long-term prescribed medication.[425–427] The Advanced IBD Nurse has the knowledge required to sensitively discuss issues that may affect a patient's compliance. This may mean regular contact for reassurance and guidance, and for encouraging the patient's independence in managing their disease through a guided self-management programme, with ongoing support as required.[423]

5.4. The Advanced IBD Nurse and e-health

Since publication of the first N-ECCO Consensus Statements,[1] care delivery in IBD has evolved to incorporate greater use of self-management and e-health platforms, and Advanced IBD Nurses play a significant role in the development of these services.[313,314,428,429] E-health in IBD refers to self-managed interactive web-based disease-monitoring tools that have been developed to individualize treatment and optimize patients' self-management, adherence, and quality of life. A number of telemedicine systems have been developed, often managed by Advanced IBD Nurses. The growth in email and text message communication, led by the Advanced IBD Nurse, is both acceptable to patients and cost-effective.[430] Telemedicine applications, such as teleconsulting and tele-education, improve treatment adherence, quality of life, and disease knowledge. Structured or shared decision-making support for patients and caregivers via e-health platforms may lead to more effective and efficient patient decision-making, decreased psychosocial distress, and, ultimately, improved outcomes.[1,418,431] The development of e-health platforms reflects the increase in roles, responsibilities and influence of Advanced IBD Nurses as services in IBD care have increased.

5.5. The Advanced IBD Nurse and research

N-ECCO Statement 5B

The importance of conducting robust empirical nursing research has been recognized across Europe [EL3]. More nurse-led research in IBD is being undertaken, and a variety of methodologies are being used to explore interventions, describe living with IBD, and evaluate the care of patients with IBD [EL3]. Continuing IBD Nurse–led research is essential, and is an important aspect of the Advanced IBD Nurse role.

Robust empirical research supports IBD Nurses' clinical practice and demonstrates the value of the Advanced IBD Nurse. Across Europe, greater support for research is now available locally via collaboration with clinical colleagues, and internationally via the growing N-ECCO Research Forum. Advanced IBD Nurses are increasingly undertaking original research within the field of IBD care, using a variety of different methodologies. Examples of nurse-led research include studies describing living with IBD,[432,433] and evaluating care and choice of care of patients with IBD.89,261,434

Advanced IBD Nurses have also led studies exploring the development of new patient assessment tools,[34] a continence assessment tool,[152] and several studies aiming to explore and understand fatigue.[225,435,436] A recent N-ECCO collaboration to identify research priorities will be used to influence ongoing IBD nursing research across Europe.[437]

6. Conclusion

IBD is a complex chronic condition requiring expert nursing care and management within the context of the MDT. These updated Consensus Statements build upon the original document[1] to provide contemporary guidance at local, national and international levels of IBD nursing care. The Statements are intended to inform, inspire, and improve the standards of IBD care, providing evidence-based guidance enabling IBD Nurses to move from fundamental to

advanced care, and encouraging research by IBD Nurses. The evidence underpinning these Statements may assist in developing business cases for supporting the appointment of IBD Nurses in new and expanding IBD services and will also work as a base when creating educational programmes for IBD Nurses.

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References

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