

# Framework for Professional Practice for Nurses Working in Inflammatory Bowel Disease in Adult and Paediatric Care Settings

CLINICAL PROFESSIONAL RESOURCE



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# Foreword

It is a great pleasure to see the Royal College of Nursing (RCN) supporting inflammatory bowel disease (IBD) nursing to develop this much anticipated professional practice framework for nurses involved in the care of children and adults with IBD.

IBD nursing as a specialism came into existence in the mid-90s. At that time there was very little by way of education available to those of us with an interest in IBD and many services were developed in isolation. However, the establishment of the RCN IBD Network (which comes under the RCN's Gastrointestinal Forum) in the early 2000s did allow for great networking opportunities, sharing of information and support.

This sharing of information has allowed and empowered IBD nurses to change their roles significantly over time. This has led to larger IBD nurse teams providing a variety of services to their patient group. It is well recognised that no multidisciplinary team (MDT) looking after IBD patients is complete without an IBD clinical nurse specialist (CNS).

Thankfully, there is now a wide variety of training and educational opportunities available for IBD CNS including Master's level courses for advanced clinical practice, university accredited IBD specific modules, RCN IBD Advanced Practice credentialing (supported by Crohn's & Colitis UK) and bespoke industry-supported educational events, programmes and conferences, both in the UK and abroad. Alongside formal programmes of education, such opportunities also give way to invaluable opportunities for networking, education and practice development.

It is vital to maintain safety for all our patients, regardless of where they are looked after, and this professional practice framework will enable nurses, their managers, and their patients to have a clear vision of what can be expected of IBD nursing roles and how these can vary depending on education and experience. This will allow for the targeting of education to meet the needs of the roles.

The ever-changing landscape of health care will remain a challenge for health care professionals including IBD CNSs. This framework for professional practice will provide much needed guidance and support for nurses to develop themselves and their teams for the ongoing benefit of their patients. It also acknowledges the many and varied roles within the field of IBD nursing and the need for training and development, as well as ongoing support from managers to enable growth within IBD nursing teams.

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# Introduction

This document provides a framework for professional practice for IBD Clinical Nurse Specialist (CNS) in clinical practice to support role development, replacing the original *'Role Descriptives for the IBD Specialist Nurse'* document published in 2007 (RCN, 2007).

An Inflammatory Bowel Disease (IBD) CNS is a qualified nurse with specialist expertise in caring for people of all ages with IBD as a core part of a multi-disciplinary team (MDT). They are responsible for leading and managing a caseload of patients; providing diagnoses, care planning, treatment, follow up and continuity of care. The role encompasses the four pillars of advanced practice: clinical practice, leadership, facilitation of education and learning, and evidence research and development (RCN, 2018).

In some adult and paediatric settings the role of IBD CNS may be combined with other gastroenterology roles or referred to as a Gastroenterology CNS, however for the purposes of this document they will be included as an IBD CNS.

At least 500,000 people in the United Kingdom (UK) live with Crohn's disease (CD) or ulcerative colitis (UC) and the numbers affected are rising (IBD UK, 2021; CCUK, 2022). These conditions are lifelong, relapsing and remitting, and patients are often diagnosed at a young age. Lifetime costs to the NHS associated with IBD care are comparable to diabetes or cancer.

National audits and benchmarking demonstrate that patients with IBD experience variable care quality across the UK. IBD CNSs empower patients by helping them understand their condition, supporting self-management and shared decision-making, and delivering planned and responsive, patient-centred care. Patients often describe their IBD CNS service as a lifeline (Mason, 2017). Easy access to an IBD CNS at times of relapse to support self-management is central to responsive, sustainable, quality care and good clinical outcomes. Evidence shows that without access to an IBD CNS, patients are more likely to require emergency intervention or they fall out of specialist services care (Kemp and UK IBD Audit Steering Group, 2010).

Using advanced nursing knowledge and skills, IBD CNSs can deliver services to IBD patients from diagnosis to continuing care throughout their lives. The IBD CNS is able to deliver prudent health care using virtual modalities and advice lines to promote and encourage patient-led, patient-focused care models (IBD UK, 2019; IBD UK, 2021). Other services typically provided are follow-up face-to-face and virtual clinics, rapid access clinics, timely admission, in-patient support and managing complex, high-cost drug pathways (Mason, Holbrook et al., 2012). By working with other clinicians, commissioners, and NHS leaders, IBD CNSs can also transform patient pathways, facilitating diagnosis, moving care closer to home and redesigning the service to meet patient needs.

# Aims of this framework for professional practice

This professional practice framework aims to clarify IBD advanced and specialist nursing roles at different levels. It also aims to provide support for the development of roles in IBD nursing, to improve access for patients and reduce variability in care. It is intended to strengthen IBD nursing and support all four UK nations' challenges regarding recruitment, retention, sustainability, benchmarking and succession planning. The framework can be used to:

- support IBD CNSs and their managers with individual personal development plans (PDPs) and continuous professional development (CPD)
- support robust career progression for IBD CNSs
- provide organisations with a framework to develop IBD CNS roles
- provide a benchmarking tool for all IBD CNS roles
- define knowledge and skills across the four pillars of advanced practice
- work alongside other national and local competency frameworks and guidelines (for example, prescribing, assessing, and monitoring biologic therapies).

## Background to the IBD CNS role and key publications

The development of nurses' roles from novice to expert was first described by Benner (1982). The evolution of IBD nursing can be seen to follow the same trajectory. In its infancy, Sheila Phillips (1995), described the emergence of the role to support individuals with IBD in terms of improving education and access to the IBD team. Similarly, at the same time discussions began to arise around the development of nurse practitioner roles and advanced practice began (Castledine, 1995).

In 2000, the first data on the impact of an IBD CNS service was published. A reduction in outpatient visits, combined with a reduction in admission and inpatient length of stay was reported with increasing numbers in remission; improved patient satisfaction was demonstrated (Nightingale, Middleton et al., 2000).

Since then, a vast array of publications have emerged supporting and evidencing the need for specialist practice within IBD. All acknowledging that IBD nursing has been recognised as a vital part of any IBD service as demonstrated by the growing recognition in the British Society of Gastroenterology Guidelines (BSG) (Carter, Lobo et al., 2004; Mowat, Cole et al., 2011; Lamb, Kennedy et al., 2019). The latest BSG guidelines describe the role as essential in management of medication, promotion of medication adherence, education, and provision of disease specific information for patients. The guidelines also outline the role of the IBD CNS in improving access to expert advice through advice line provision, and co-ordination of outpatient follow up.

In 2009, South Bank University published a systematic review of the effectiveness of the IBD CNS (Belling, McLaren et al., 2009). On reflection, the infancy of the specialism reflected the main recommendations from the systematic review, which were:

- to identify a common set of skills, knowledge and competencies required of IBD CNSs
- to identify the educational preparation necessary for IBD CNSs and their ongoing training and development needs
- to carry out a scoping exercise to identify the number of IBD CNSs currently in post, their scope and model of practice, and the contexts in which they operate
- for prospective, rigorously designed studies, exploring the clinical and cost effectiveness of the IBD nursing role.

National audits of IBD CNS roles in 2012 (Mason, Holbrook et al., 2012) and 2019 (Younge, Mason et al., 2021) have mapped the workforce across the UK showing significant increases in the number of posts nationally. In 2017, Crohn's & Colitis UK commissioned a study to define a patient caseload for the IBD CNS. This led to the collection of data from 164 nurses covering over 146,000 patients. The study demonstrated that IBD CNSs are involved in all stages of the treatment pathway with their highest activity post diagnosis.

Additionally:

- for the first time a pre-diagnostic role was identified with 59% of nurses reporting seeing patients before they were diagnosed
- 63% of respondents had a higher caseload than the recommended level



- IBD CNSs contributed a considerable amount of unpaid overtime (4.13 hours per week each on average) to cope with the needs of their patient population
- while almost half (43%) of IBD CNSs had a prescribing qualification, only 14% had a Master's degree in Advanced Practice, the current standard for credentialing with the RCN for advanced level practice (Younge, Mason et al., 2021).

Through a process of workforce modelling, the study recommended increasing the IBD CNS workforce to 2.5 whole time equivalent (WTE) per 250,000 population with a maximum of 500 patients per full time CNS at any one time (this was an increase from 1.5 WTE per 250,000 population within the IBD standards.) Currently there are no such recommendations within a paediatric setting. This recommended caseload standard was embedded into multidisciplinary national IBD Standards (Kapasi, Glatter et al., 2020) which enable teams to benchmark and progress their service.

The support for the IBD CNS role from the clinical community is not unique to the UK. The European Crohn's & Colitis Organisation (ECCO) and their nursing section (N-ECCO) have published many in-depth consensus guidelines, topical reviews and position statements that describe quality clinical care and the IBD nursing role, including at an advanced level (O'Connor, Bager et al., 2013; Kemp, Dibley et al., 2018), as well as the benefit of MDT working (Panés, O'Connor et al., 2014).

On review of the evidence, the underpinning driver for nurses working within the IBD specialty is to improve patient care and promote positive experiences for individuals with IBD. The support is valued by patients and their families' (Belling, Woods et al., 2008). More recently the impact of nursing roles on psychological wellbeing has been published, noting the positive impact upon physical symptoms (Byron, Cornally et al., 2020; Ma, 2020).

It is clear to see the development of the IBD CNS role since the previous publication of the *role descriptives* document back in 2007, the value of the role to organisations, the wider health care community and most importantly to individual patients. The authors acknowledge that there is a need for further research, evaluation, and audit to capture the unique contribution of the IBD CNS and the impact the role has on patient experience of living with IBD.

## Paediatric IBD CNS practice

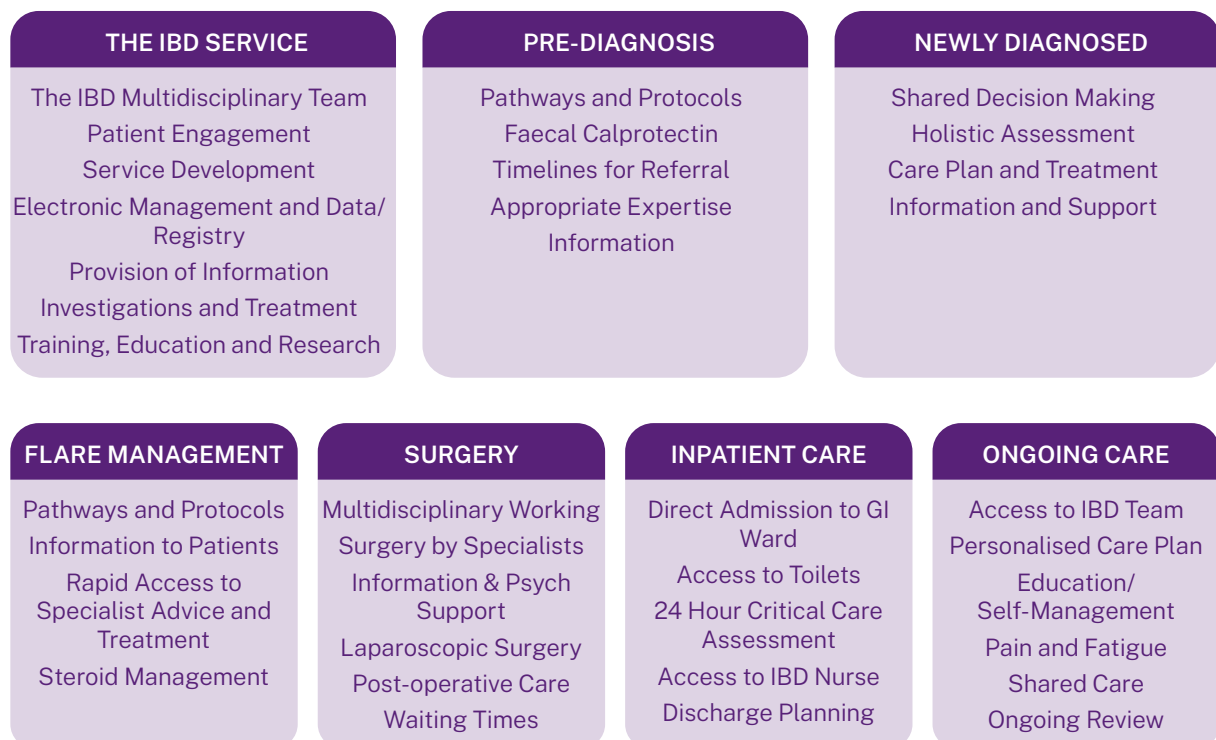
The original *role descriptives* paper published in 2007 focused on the IBD CNS role caring for adults (RCN, 2007). This current framework for professional practice has been written in a format that encompasses the varied scope of practice across individual IBD nursing roles, including paediatric nursing. Although the attributes of the IBD CNS are primarily the same for both paediatric and adult IBD nurses, it is recognised that there are key differences in how care is delivered. This includes the pivotal role the family plays in the care of a child, resulting in a variety of information needs. There are differences in how treatments are used to reflect the pharmacokinetics and pharmacodynamics of the child and licensing limitations to be considered. More information can be found in paediatric specific guidelines (Turner, Ruummele et al., 2018; Van Rheenen, Aloï et al., 2021).

CNSs working in paediatrics are less likely to have a sole focus on IBD and often cover other areas of practice such as nutrition, motility and hepatology. This framework focuses on IBD-specific roles but should not distract from other areas of practice.

Safeguarding, although not unique to paediatrics, is an important consideration within all paediatric nursing, including that of the IBD CNS. Local policies should be followed where there are concerns. For a large proportion of the paediatric patient population, there is a need to liaise with other essential services around the child, such as the school, general practitioner (GP), community nurses and social workers, as well as adult services for those patients who are involved in adolescent transition. Transition is a key aspect in the role of the paediatric IBD CNS, who will often remain the allocated person of contact and support for the young person during this time, encouraging autonomy, confidence and increased responsibility of the young person as they move towards adult services.

# Service standards – IBD UK core statements

In 2009 the first national IBD Standards were published to improve standards and reduce variation of care across the UK. They provide a benchmarking tool which can be used by health care services to audit their provision and identify areas for improvement. The seven sections of the IBD Standards are shown in the diagram below.



IBD Standards reproduced with permission from IBD UK [www.ibduk.org/ibd-standards](http://www.ibduk.org/ibd-standards)

# Defining and describing levels of practice

Patients diagnosed with IBD will encounter nurses working at different levels of practice and with different role titles (such as staff nurses, CNSs and ANPs) as well as across different care settings (for example, infusion units, out-patient clinics, hospital wards or endoscopy units). The evolution of individual nurses' practice and competence within the specialty develops over time through education, knowledge, experience, and expertise reflecting Benner's five stages of proficiency demonstrated within the novice to expert model (Benner, 1982).

Each of these roles requires different levels of knowledge and skills. It is recognised that specialist knowledge can be applied across all levels of professional practice. Policy documents across the four UK nations have started to describe 'levels' of practice for health care professionals across the career pathway. These levels range from 'supportive' to 'consultant' and are overlapping in recognition that, as practitioners develop, or if they change clinical role, their levels of skill and knowledge may move between levels (HEE, 2017; DH, 2018; NLIAH, 2020; NES 2021).

The term 'enhanced' was chosen following the early scoping of the RCN Professional Framework programme and a roundtable meeting held to discuss specialty practice in 2019. The definition of 'enhanced level' is in its infancy and used as the level before advanced practice. These levels of practice are not disease-area specific but help to define a framework for roles and consistency of nursing practice across specialties. Nurses work within specialties across the various levels of practice. The RCN will be developing an overarching professional framework for nursing that will include levels of practice.

This *Framework for Professional Practice for Nurses Working in Inflammatory Bowel Disease in Adult and Paediatric Care Settings* focuses on the three levels relevant to the nursing practice of those working as CNSs, ANPs, or consultant nurses within the specialty of IBD. These levels are: enhanced, advanced and consultant.

# Attributes of the IBD CNS

Registered nurses are expected to exhibit professional standards of practice and behaviour as set out by the Nursing and Midwifery Council (NMC) (2018). At the point of registration, the NMC expects every nurse across all fields of nursing practice and all care settings to have the following proficiencies.

- Being an accountable professional.
- Promoting health and preventing ill health.
- Assessing needs and planning care.
- Providing and evaluating care.
- Leading and managing nursing care and working in teams.
- Improving safety and quality of care.
- Co-ordinating care.

Nurses working in specialist (enhanced), advanced or consultant roles will not only be required to meet these fundamental proficiencies. They will also need to develop the necessary expertise, knowledge and experience to ensure they are able to meet the increasingly complex holistic needs of patients with IBD, along with evolving regulatory requirements and professional standards of advanced practice (NMC, 2018).

# Preparation for practice as an IBD CNS

Every nurse's career journey to an IBD CNS role is different, as is the existing skill set they bring to the role. Therefore, there is no formal pathway or practice preparation for those who wish to enter a career in IBD nursing. Those planning entry into an IBD CNS post may consider:

- connecting with an IBD CNS service to understand:
  - role requirements and person specification
  - how an IBD service operates
  - how patients are managed within that service
  - patients' experiences of living with IBD
  - diversity of the IBD CNS role and the desirable skills and attributes
- what transferrable skills they have, and what they would need to develop
- whether they have the attributes required of an IBD CNS: [www.crohnsandcolitis.org.uk/our-work/healthcare-professionals](http://www.crohnsandcolitis.org.uk/our-work/healthcare-professionals)
- developing fundamental knowledge of the pathophysiology and management of IBD.

## Tips for IBD CNS new in post

It can be daunting to be a new IBD CNS and some may find the transition from a non-CNS role challenging. The following can support the early development of a career in IBD nursing.

- Having a clear job description and realistic job plan (with scope for role development).
- Understanding the expected scope of practice – and what skills, training and knowledge are required to fulfil this.
- Being clear of the purpose, and limitations of the role.
- Identifying a mentor or clinical supervisor within the service to support training in practice.
- Having career conversations with line managers to plan professional development and training needs.
- Being aware of local or national educational resources.
- Joining the RCN's Gastrointestinal Forum and IBD Network (regional groups and a national closed Facebook group) for networking, peer support and advice.



### Example educational resources to support an IBD CNS develop through their career

University-based education	Professional groups	Pharmaceutical industry-led education	Local resources	Patient organisations
<p>Management of Inflammatory Bowel Disease module (Level 7 Salford University)</p> <p>Advanced clinical assessment and decision making</p> <p>Non-medical prescribing</p> <p>Research modules</p> <p>Health care professionals working at advanced and consultant level are expected to be educated to Master's degree level in clinical practice (which could include the clinical assessment and prescribing modules)</p>	<p>RCN IBD Network: <a href="http://www.facebook.com/groups/RCNIBDNetwork">www.facebook.com/groups/RCNIBDNetwork</a></p> <p>RCN Gastrointestinal Forum: <a href="http://www.rcn.org.uk/get-involved/forums/gastrointestinal-nursing-forum">www.rcn.org.uk/get-involved/forums/gastrointestinal-nursing-forum</a></p> <p>British Society of Gastroenterology: <a href="http://www.bsg.org.uk/clinical-articles">www.bsg.org.uk/clinical-articles</a></p> <p>European Crohn's &amp; Colitis Organisation: <a href="http://www.ecco-ibd.eu/education.html">www.ecco-ibd.eu/education.html</a></p> <p>Royal College of General Practitioners: IBD e-learning module <a href="http://www.elearning.rcgp.org.uk/course/info.php?id=271">www.elearning.rcgp.org.uk/course/info.php?id=271</a></p> <p>IBD toolkit: <a href="http://www.elearning.rcgp.org.uk/mod/book/view.php?id=12536">www.elearning.rcgp.org.uk/mod/book/view.php?id=12536</a></p>	<p>Company-led regional or national meetings</p> <p>Some examples of wider support are:</p> <p>Takeda's IBD Empower: <a href="http://www.ibdempower.com">www.ibdempower.com</a></p> <p>Tillotts LOGIC Education: <a href="http://www.logic-tillotts.co.uk">www.logic-tillotts.co.uk</a></p>	<p>IBD team training</p> <p>Local GI/IBD professional networks</p> <p>Leadership training</p>	<p>Crohn's &amp; Colitis UK: <a href="http://www.crohnsandcolitis.org.uk">www.crohnsandcolitis.org.uk</a></p> <p>IBD Relief: <a href="http://www.ibdrelief.com">www.ibdrelief.com</a></p> <p>CICRA (Crohn's in Childhood Research Association): <a href="http://www.cicra.org">www.cicra.org</a></p>

# Framework for professional practice for nurses working in IBD

This professional practice framework describes knowledge and skills at enhanced, advanced and consultant levels across the four pillars of advanced practice: clinical practice, evidence research and development, facilitating education and learning, and leadership (RCN, 2018).

IBD CNSs will practice at different levels depending on local needs and individual abilities. This professional practice framework **aims to provide guidance** to the development of the IBD CNS career pathway and support development conversations within local organisations. At the same time, it recognises that some roles may remain within one level of practice.

It is expected that if, and when, a nurse progresses through the levels of practice they have the skills associated with earlier levels and that this is not a linear process. Each level of clinical practice brings its own values and benefits and, as such, there is no expectation that every IBD CNS will, or should, develop to advanced or consultant level. For example, enhanced practice is preparation for advanced practice but may also be the level at which nurses choose to stay.

The clinical, research, education and leadership skills cited are illustrative and not mandatory. Nurses may undertake the clinical procedures and skills cited according to their specific area of practice and competence. It is not expected that all nurses will undertake all procedures cited.

The framework does not determine or define pay grading across levels of practice. Grading at a local level will be determined by a combination of factors including level of clinical autonomy and responsibility for practice and service delivery, combined with leadership in the broader domains of practice.

This framework should be used alongside local or national guidelines.

**Abbreviations will be used, please refer to the glossary for more details.**

## Clinical practice

ENHANCED	ADVANCED	CONSULTANT
<p>On diagnosis of IBD, facilitates a full assessment of the patient's disease <b>within their scope of practice</b>.</p> <p>This may include:</p> <ul style="list-style-type: none"> <li>• disease mapping</li> <li>• differentiating between Crohn's disease and ulcerative colitis</li> <li>• identifying phenotype</li> <li>• extent and severity of disease.</li> </ul> <p>Has appropriate, up-to-date, clinical education consistent with local and national guidelines/ the role, including understanding of the pathophysiology and management of IBD.</p> <p>This would be demonstrated through clinical history taking, endoscopic and radiological assessment of the patient using local guidelines or protocols.</p> <p>Interprets endoscopic, radiological and histological findings, and escalates care accordingly.</p> <p>Uses comprehensive skills for assessment, diagnosis, treatment and evaluation to provide personalised plans of care within own scope of practice using appropriate guidelines and protocols.</p> <p>This may include:</p> <ul style="list-style-type: none"> <li>• interpreting investigation results</li> <li>• triage of the patient</li> <li>• developing plans of care</li> <li>• signposting to support networks</li> <li>• onwards referral to endoscopy and radiology</li> </ul>	<p>Receives referrals for new/suspected and established patients.</p> <p>Has appropriate, up-to-date, clinical education including advanced assessment skills and non-medical prescribing (in line with local guidelines or protocols).</p> <p>Uses advanced clinical skills and judgement in managing complex and unstable IBD. As an autonomous practitioner assesses, plans, implements and evaluates care for patients. This may include:</p> <ul style="list-style-type: none"> <li>• assessment of IBD (including unstable or complex disease) through clinical history taking and onward referral to endoscopy, radiology, surgery and other appropriate specialties</li> <li>• assessment of perianal Crohn's disease, including: <ul style="list-style-type: none"> <li>- requesting of MR pelvis</li> <li>- requesting endoscopy</li> <li>- referring to surgical teams for assessment</li> </ul> </li> <li>• rationalising the appropriate requesting of investigations based on ECCO/BSG/ESPGHAN guidelines and within local protocol and following appropriate training (for example, IR(ME)R) and act appropriately on findings (such as differentiating between the use of CT/MR scan).</li> </ul> <p>Autonomously develops treatment plans and escalates treatment within ECCO/BSG/ESPGHAN guidelines to prevent complications developing. This may include escalation to biologic therapy.</p>	<p>Has a recognised role within the MDT in complex decision making and care planning for IBD patients.</p> <p>Autonomously manages their own caseload.</p> <p>Provides clinical leadership to contribute to improved patient outcomes.</p> <p>Ensures a strong nursing voice at all levels within organisational strategy, and in regional, national and international networking.</p> <p>Uses advanced knowledge and contributes to local, national and/or international guidelines and innovations related to patient care and delivery.</p> <p>Works in collaboration with other specialties to deliver multi agency and patient responsive services to IBD patient needs aligned with hospital policies.</p> <p>Has a recognised role within the MDT in complex decision making and care planning for IBD patients.</p> <p>Autonomously manages their own caseload.</p> <p>Provides clinical leadership to contribute to improved patient outcomes.</p> <p>Ensures a strong nursing voice at all levels within organisational strategy, and in regional, national and international networking.</p> <p>Uses advanced knowledge and contributes to local, national and/or international guidelines and innovations related to patient care and delivery.</p>

ENHANCED	ADVANCED	CONSULTANT
<ul style="list-style-type: none"> <li>• rationalising the modalities of investigations in informing the clinical assessment</li> <li>• assessing delayed growth in children and adolescents; considering delayed puberty in adolescents</li> <li>• completing and interpreting disease activity scores (for example, HBI, Mayo score, CDAI, SCCAI, PCDAI, PUCAI).</li> </ul> <p>Assesses the psychological and social impact of diagnosis on the patient. This should consider:</p> <ul style="list-style-type: none"> <li>• sexual function</li> <li>• mental health</li> <li>• employment/education</li> <li>• relationships</li> <li>• fatigue</li> <li>• faecal incontinence</li> <li>• pain</li> <li>• body image.</li> </ul> <p>Assesses for extraintestinal manifestations of IBD referring on as appropriate, including:</p> <ul style="list-style-type: none"> <li>• nutritional status</li> <li>• bone health such as development of osteoporosis and fracture risk</li> <li>• ocular disease (for example, anterior uveitis or episcleritis)</li> <li>• rheumatological (including axial and peripheral arthropathies)</li> <li>• dermatological (for example, erythema nodosum or pyoderma gangrenosum)</li> <li>• oral diseases (for example, aphthous ulcers).</li> </ul>	<p>Considers treatment plans on a personalised basis reflecting patients’ comorbidities.</p> <p>Provides leadership in the care of in-patients with IBD including supporting and advising other members of the nursing and MDT as appropriate.</p> <p>Assesses response to treatment and leads discussions around treatment escalation or referral to surgery. This includes:</p> <ul style="list-style-type: none"> <li>• interpretation of blood tests, including inflammatory markers, faecal calprotectin</li> <li>• interpretation of drug levels (TGN/TDM), escalating and optimising therapy based on these results</li> <li>• disease mapping, extent and severity of the disease. This should be demonstrated through clinical history, endoscopic and radiological assessment of the patient.</li> </ul> <p>Proactively manages the prevention of complications of IBD. This includes:</p> <ul style="list-style-type: none"> <li>• requesting DEXA scans in line with NICE guidelines and reducing the risk of long-term steroid use using adjuvant calcium or bisphosphonate therapy</li> <li>• completing colorectal cancer screening in line with BSG guidelines</li> <li>• demonstrating understanding of endoscopic and histological findings.</li> </ul> <p>Undertakes complex conversations with patients/ carers to inform of diagnosis, complications, and treatment plans.</p>	<p>Works in collaboration with other specialties to deliver multi agency and patient responsive services to IBD patient needs aligned with hospital policies.</p> <p>Identifies and challenges boundaries and traditions, translating regional, national, and international priorities into own systems.</p>

ENHANCED	ADVANCED	CONSULTANT
<p>Completes pre-immunosuppressant and biologic opportunistic infection screening in line with ECCO or local guidelines and identifies the need for appropriate vaccinations in accordance with local policy.</p> <p>Interprets blood tests, including inflammatory markers and faecal calprotectin.</p> <p>Interprets drug levels such as TDM or TGN including appropriate pre-treatment investigation.</p> <p>Uses highly-developed communication skills and actively listens to and understands the patient's concerns, experiences and opinions. This includes the use of verbal and nonverbal communication skills, along with active listening and reflection.</p> <p>Discusses results to develop care in partnership with patients/carers.</p> <p>Identifies and escalates patients requiring treatment optimisation.</p> <p>Recognises own level of ability and competency, referring to others as necessary.</p> <p>Contributes to MDT discussions as patient advocate.</p> <p>Audits care pathways and contributes to service improvements and development.</p> <p>Has an awareness of safeguarding policies and is able to identify and escalate concerns appropriately.</p> <p>Is aware of and/or involved in the transition of patients from adolescent to adult IBD services. Paediatric CNSs predominantly undertake the role of Named Key Worker.</p>		

## Leadership

ENHANCED	ADVANCED	CONSULTANT
<ul style="list-style-type: none"> <li>• Proactively develops relationships within the IBD team and with patients/carers, to encourage productive working.</li> <li>• Actively participates in local IBD nurse network groups.</li> <li>• Engages in national IBD Standards benchmarking.</li> <li>• Contributes to quality improvement and service development.</li> <li>• Actively seeks out feedback from colleagues, other members of the IBD team and those living with Crohn's disease and ulcerative colitis and their family and carers.</li> <li>• Offers expert advice, both to the IBD team and to others through direct and indirect patient care. Refers on more complex queries.</li> <li>• Raises risk issues within the IBD service and participates in investigation and management change.</li> <li>• Contributes to the IBD service operational policy and annual report.</li> <li>• Participates in, and contributes to, regular clinical supervision of team members.</li> </ul>	<ul style="list-style-type: none"> <li>• Leads, develops, and evaluates new guidelines and protocols relevant to all IBD pathways.</li> <li>• Leads the development of cross-boundary working, referral pathways across primary and secondary care. This may include:                             <ul style="list-style-type: none"> <li>- using the RCGP toolkit to support and educate staff in primary care</li> <li>- leading the development of cross- boundary protocols for the management of suspected IBD, and management of unstable disease.</li> </ul> </li> <li>• Holds a leadership role within the IBD team, engaging stakeholders and uses high-level negotiation and influencing skills to improve patient outcomes.</li> <li>• Leads on the implementation of the national IBD standards within their local organisation.</li> <li>• Provides professional and clinical advice to colleagues regarding IBD management, the development of IBD practice and service improvement.</li> <li>• Leads the evaluation of practice through audit and service review to demonstrate impact. This should include local and national audits.</li> <li>• Has an active or leadership role within local IBD networks.</li> <li>• Instigates and leads patient engagement in service improvement involving individuals, families, carers and colleagues.</li> <li>• Understands the impact of an IBD diagnosis on the whole family.</li> </ul>	<ul style="list-style-type: none"> <li>• Understands the impact of IBD including patients' needs pre- and post-diagnosis and long-term monitoring needs. Is able to plan the IBD service accordingly.</li> <li>• Develops collaborative relationships with external partners for example, Crohn's &amp; Colitis UK, BSG, RCN, N-ECCO.</li> <li>• Works across clinical teams, facilitating networking.</li> <li>• Ensures patient collaboration, including co-production and co-design across sectors and organisations.</li> <li>• Leads programmes or projects with other IBD consultants promoting regional/national/ international service development.</li> <li>• Innovates and leads job plans to encompass new roles.</li> <li>• Sets standards for practice, for example, implementing national and international guidance or standards such as BSG, RCN, N-ECCO guidance, and IBD UK national standards.</li> <li>• Leads the dissemination of quality improvement work, publishing and presenting impact.</li> <li>• Initiates, designs and facilitates local patient involvement across boundaries, for example, primary to secondary care.</li> <li>• Facilitates and enables others in the IBD team to take on leadership responsibilities.</li> </ul>



ENHANCED	ADVANCED	CONSULTANT
	<ul style="list-style-type: none"> <li>• Offers advice in non-standard, complex clinical situations, through direct and indirect patient care.</li> <li>• Leads incident reporting, investigation and management.</li> <li>• Takes responsibility for the IBD nursing service operational policy and annual report.</li> <li>• Provides clinical supervision to colleagues/peers.</li> </ul>	<ul style="list-style-type: none"> <li>• Works with a network of leaders (for example, other senior IBD nurse specialists, medical consultants, senior AHPs) to deliver service, organisational and system-wide service improvement.</li> <li>• Anticipates and acts on health trends relevant to IBD care (all pathways) and leads strategic service planning to ensure response.</li> <li>• Provides expertise and acts as an ambassador for IBD nursing at national and international levels, for example, invited keynote speaker.</li> <li>• Provides clinical expertise within the service or organisation, with senior NHS leaders and commissioners.</li> <li>• Offers consultancy and leadership in complex investigations, negotiating conflict and achieving consensus.</li> <li>• Disseminates annual reports, ensuring all senior NHS leaders are engaged. Leads system reviews and business planning.</li> </ul>

## Facilitating education and learning

ENHANCED	ADVANCED	CONSULTANT
<b>Educational preparation for practice</b>		
<p>Preparation beyond the level of a generalist nurse within IBD. Demonstrates learning within:</p> <ul style="list-style-type: none"> <li>• anatomy and physiology</li> <li>• aetiology of IBD</li> <li>• management of IBD.</li> </ul>	<p>Holds a Master's degree/recognised credentialing recognition or equivalent within IBD.</p>	<p>Works towards/holds doctorate level qualification.</p>
<b>Continuing professional development (self)</b>		
<p>Critically assesses and addresses own learning needs, negotiating a PDP that reflects the needs of the practitioner and IBD service. This may include formal university education, such as specialist IBD modules or non-medical prescribing. It may also include other sources of education, such as pharmaceutical-led programmes, training delivered by professional bodies such as BSG or ECCO, and locally developed networking opportunities such as RCN IBD Network and Gastrointestinal Forum.</p> <p>Actively seeks feedback about how own behaviour and values impact on others and develops learning needs based upon feedback.</p> <p>Has well-established local professional networks and collaborations associated with IBD.</p> <p>Uses effective spaces to enable self-reflection, sense making and reflective reviews.</p>	<p>Critically assesses and addresses own learning needs, negotiating a PDP that reflects the breadth of ongoing professional development across the four pillars of advanced practice in relation to IBD.</p> <p>Has well-established regional and national professional networks and collaborations associated with IBD.</p> <p>Uses self-reflection to rationalise and navigate higher-level of reasoning.</p>	<p>Seeks opportunities to develop knowledge and skills within all four pillars.</p> <p>Continues to develop a portfolio of practice development, scholarship and research and is recognised as an expert and innovator in the field of IBD.</p> <p>Has well-established regional, national and international interprofessional networks, collaborations and sphere of influence associated with IBD.</p>

ENHANCED	ADVANCED	CONSULTANT
<b>Continuing professional development (others)</b>		
<p>Advocates for, and contributes to, a culture of organisational learning to inspire future and existing nurses within IBD.</p> <p>Develops relevant educational materials for patients and staff – including non-specialist staff.</p> <p>Facilitates educational opportunities and supports other nurses and health care professionals in complex clinical situations.</p> <p>Acts as a role model, educator, supervisor, coach and mentor, seeking to instil and develop the confidence of others.</p>	<p>Works in collaboration with others to mentor, supervise and coach, or assess, plan and deliver interventions to meet the learning and development needs of their own and other health care professionals.</p> <p>Facilitates collaboration of the wider team and supports peer review processes to identify and address individual and team learning and development needs.</p> <p>Supports the wider team to build capacity and capability through work-based and interprofessional learning, and the application of learning to practice.</p>	<p>Leads the development of organisational learning to support the development of nursing practice and patient care within IBD.</p> <p>Leads the development of systems of coaching, mentorship and role modelling to develop IBD clinical practice and patient care across primary and secondary care.</p> <p>Works with key stakeholders, including higher education institutions, patient organisations and other education providers, to develop and promote a range of learning opportunities.</p> <p>Leads learning and development processes that support blended approaches (for example, e-learning) to learning. Promotes reciprocal learning (for example, mutually working across disciplines) adapted to individual learning styles and motivation.</p> <p>Shares outcomes within the organisation regionally and nationally.</p>
<b>Patient education</b>		
<p>Engages with, appraises and responds to patients' and carers' motivations, development stages and capacities. Works alongside them to support health literacy and empowers them to participate in decisions about their care to maximise their health and wellbeing.</p>	<p>Ensures the development of information and programmes, and monitors the effectiveness of them, making revisions in accordance with patient feedback, outcome measures and the latest clinical evidence and national guidance.</p>	<p>In partnership with patients, clinical leaders, managers and educators, promotes and facilitates positive learning environments and influences the strategic development of organisational learning to enhance patients' experiences of services.</p>
<p><b>Other:</b></p> <p>Demonstrates knowledge of various teaching methods and learning styles in everyday practice and can adapt teaching style to audience.</p>		

## Evidence research and development

ENHANCED	ADVANCED	CONSULTANT
<p>Demonstrates understanding of how to identify and begin to critique relevant research, evaluations and audits and see how they apply to IBD practice.</p> <p>Evaluates and audits IBD service provision (such as benchmarking against IBD standards within local organisations), selecting and applying valid, reliable methods, then acting on the findings.</p> <p>Critically engages in IBD research activity, adhering to good clinical practice guidance, so that evidence-based strategies are developed and applied to enhance quality, safety, productivity and value for money.</p>	<p>Critically appraises and synthesises the outcomes of relevant IBD research, evaluations and audits, using the results to underpin own practice and to inform that of others.</p> <p>Actively undertakes own original IBD nursing research, possibly through MSc level education.</p> <p>Takes a critical approach to identifying gaps in the evidence base for IBD nursing and its application to practice, including patient and carer voice.</p> <p>Facilitates collaborative links between clinical practice and research, highlighting knowledge gaps through proactive engagement, networking with academic, clinical and other active researchers (for example, through RCN IBD Network, BSG, N-ECCO/ECCO, BSPGHAN).</p> <p>Leads the ongoing development, implementation and review of IBD service pathways, standards, policies, guidelines, procedures, service improvement and national quality frameworks.</p> <p>Contributes to national and international IBD guideline development groups (for example, RCN, BSG, N-ECCO, BSPGHAN) ensuring that they remain leading edge. Acts as a peer reviewer of research, inquiry and innovation and evaluation of IBD projects locally, regionally and nationally.</p> <p>Implements formal systems for collecting and reviewing feedback from patients/service users (for example, patient panel) and staff across service. Works with the IBD team to review, identify and implement actions.</p>	<p>Leads local or national IBD research programmes.</p> <p>Contributes to national and international collaborative research, inquiry, innovation and evaluation relevant to generating new knowledge and understanding about aspects of person centred, safe and effective IBD care – embedding public and patient involvement and engagement.</p> <p>Implements and evaluates systems and measures to demonstrate progress, ensuring that people’s voices are heard in all key activities across every level of the care systems.</p> <p>Role models the integration of research with learning and practice to achieve an evidence-based approach to IBD care.</p> <p>Collaborates with key research stakeholders, identifying and disseminating sources of research funding in a strategic framework.</p> <p>Considers use of a clinical academic framework to contribute to the development of the body of IBD nursing knowledge. Achieves this through rigorous research, innovation and inquiry, as well as enabling others, building academic networks and research collaborations, and working in partnership with higher education institutions.</p> <p>Has a portfolio of nursing and clinical research, possibly through PhD level study. Actively develops and leads links with academic research partners (for example, local research networks or higher education institutions).</p>

ENHANCED	ADVANCED	CONSULTANT
	<p>Publishes novel research and audit results at relevant IBD conferences and publications.</p> <p>Facilitates collaborative reviews of IBD care/ services through IBD UK, IBD Registry and other audit, evaluation of safety, and quality and health outcomes – keeping service users voice at the heart of the process.</p>	

# Examples of the framework in practice

## Enhanced nursing example – biologics counselling

Following MDT discussion and agreed treatment plan, a nine-year-old boy is booked into the IBD CNS clinic to discuss initiation of a new biologic therapy. The boy attends with his mother. The CNS takes an up-to-date clinical assessment and history, including both gastroenterological and extra-intestinal symptoms. A social update is noted, establishing how things are at home and school, with careful consideration of the need for referral to any other services (for example, if the child would benefit from psychology, dietetic or social services input).

The CNS explains the results of recent relevant investigations (including blood and stool tests, scans and scope/histology) to the patient and his mother. They discuss with them that, in light of these results, it is felt that escalation of treatment is required in order to achieve remission of symptoms and improved quality of life.

They counsel the family about the recommended biologic, explaining how the medication works, its expected benefits, potential side-effects and risks and the required monitoring. They answer any questions that the patient and his mother have and ensure that they are happy to consent to the treatment.

The patient and his mother agree that he will start treatment. They discuss self-injection and agree to plan self-injection training. The CNS informs the referring doctor that the patient is happy to start treatment so that they can request the appropriate pre-screening investigations, and makes the required onward referral, in this case for homecare registration.

### Summary of enhanced skills and knowledge

- Able to take clinical history and interpret investigation results.
- Develops a plan of care following guidance from the MDT.
- Includes safeguarding, psychological support and social impact in assessment.
- Escalates requirement for treatment optimisation and signposts patient and family to relevant information.

## Advanced nursing example – treatment escalation

A 48-year-old man has been booked in for a nurse-led clinic review following a call to the IBD advice line with an ulcerative colitis flare, confirmed on endoscopy. During the advice line call the CNS had noted this was the second course of steroids he has required since starting azathioprine six months previously. They requested routine bloods including TGN and stool samples (infection screen and calprotectin) and arranged the clinic review to discuss the results and assess his progress.

Current medications: azathioprine 150mgs daily, mesalazine 3g daily and a reducing course of steroids prescribed by his GP.

In clinic the CNS discusses the results of the recent investigations with the patient and explains that his faecal calprotectin is elevated, indicating active disease. His bloods also show elevated CRP of 30, Hb 128, MCV 78, platelets 440. LFTs and U&Es are normal.



The patient himself reports a good response to his recent course of steroids which he is reducing by 5mg weekly as a tapering course.

The patient's TGN level is 278pmol/8x10<sup>8</sup> with 6-MMP 593. The CNS explains to the patient that these results mean his current azathioprine dose is optimised and that despite this there is evidence of ongoing active disease indicating the need to consider escalation of treatment to a biologic therapy.

The CNS explains the rationale for starting such treatment in a situation like this and outlines the options available. They have a detailed discussion with the patient regarding risks and benefits associated with biological therapies. Written information is also provided. The patient expresses that he would like to start treatment with a subcutaneous biologic therapy to fit in with his lifestyle.

The CNS requests the necessary viral screening bloods, TB interferon gamma release assay (QuantiFERON) and a chest x-ray explaining the rationale for these investigations to the patient. During the consultation, the CNS notes an additional diagnosis of coeliac disease and also requests bloods for coeliac serology to ensure that uncontrolled coeliac disease did not contribute to the recent flare. The CNS explains that if all screening tests are satisfactory, arrangements will be made to start the preferred biological therapy. They arrange follow up with the patient to share the results and confirm arrangements for initiating therapy.

### Summary of advanced skills and knowledge

- Able to recognise the need for escalation of treatment through advanced assessment and interpretation of results.
- Carries out individual care planning giving patient information and choice around next treatment opportunities.

## Consultant nursing example – providing clinical expertise and leadership

A 35-year-old woman with Crohn's disease is booked into the CNS IBD outpatient clinic for routine review whilst on biologic therapy. The patient reports to the CNS that she has not been taking her treatment as she has recently left her home address after a breakdown in her marriage and has not received delivery of her prescribed treatment. Currently she is experiencing a flare in her symptoms.

The patient is distressed and distracted, and the CNS is finding it difficult to engage and move the consultation forward, so comes to the nurse consultant's (NC's) clinic room to ask for help.

The NC joins the consultation with the CNS alongside. Using a combination of verbal and non-verbal communication to help calm the situation, the NC is able to take a clinical history and complete a physical assessment whilst reassuring and listening to the patient's concerns. During the assessment the patient explains that they don't feel safe to return home to collect their medication. The NC agrees a plan for bloods, urgent small bowel ultrasound and stool testing, and also acknowledges the wider issues for

the patient and plans close monitoring. They also arrange for a prescription of biologic to ensure the patient is able to restart therapy as soon as possible.

Next steps are agreed with the patient and CNS, and the patient agrees to referral to the hospital safeguarding lead. The NC returns to their own clinic room leaving the CNS and patient together to put the clinical plan into action. While away from the patient the NC calls the safeguarding lead, who advises on the next steps.

The patient has calmed and is confident with the CNS. The NC reports back from the safeguarding lead to them both, including sharing the plan for patient support from here.

Following clinic, the NC and CNS take time together to reflect on the interaction. They discuss the clinical, emotional and practical lessons learnt and agree how they can keep contact with the patient, the safeguarding lead and each other over coming reviews.

Later, the CNS shares their experiences at the IBD nursing team meeting, with the NC present.

### **Summary of consultant skills and knowledge**

- Leads complex decision making within the IBD nursing team.
- Provides clinical leadership that contributes to improved patient outcomes.
- Offers leadership, negotiating conflict and achieving consensus.
- Works in collaboration with other specialties to deliver multi-agency, patient responsive services to patients.

# Conclusion

Reflecting upon this framework and its evolution from the role descriptives document (RCN, 2007) it is evident how IBD specialist nursing has developed and has now become integral to raising the quality of care for patients with IBD. The IBD CNS role is recognised in national and international guidelines (Lamb, Kennedy et al., 2019; Kemp, Dibley et al., 2018) and evidence has emerged to articulate the contribution of this specialist group. The development of the advanced practice framework (RCN, 2018) recognised that the advanced practice element of CNS role is now a core part of a MDT, leading and managing a caseload of patients and providing diagnoses, care planning, treatment, follow up and continuity of care.

This framework acknowledges the progression of career pathways from early career specialist nurses within enhanced roles towards advanced and consultant roles. It provides nurses with a clear framework with which to develop their practice and to establish their individual capabilities across the four pillars of advanced practice and at each practice level. Guidance is given to employers on decision making processes that should be introduced so they understand when and how the various levels of practice should be implemented, acknowledging the scope of practice and recognising the need for protected time for research and education. It is envisaged that the new framework will be used to facilitate discussions with line managers as to how specific levels of practice would be best placed in an individual patient, family, or carers journeys for greatest impact upon the planning of the workforce and IBD services within the UK.

Finally, this framework provides a reference point for services and nurses working in advanced and consultant roles, and those aspiring to such roles. This will encourage innovative ways of working in modern teams, and support managers and the wider MDT in the development of roles and subsequent services. The framework has recognised that nursing is a dynamic profession; roles and services develop rapidly and it is envisaged that this document will provide the foundations to support career development and improve the quality of care patients with IBD receive.

## Get involved

If you are an RCN member working in IBD join the RCN's Gastrointestinal Nursing Forum to keep your knowledge up-to-date and find events in your country or region. [rcn.org.uk/Get-Involved/Forums/Gastrointestinal-Nursing-Forum](https://rcn.org.uk/Get-Involved/Forums/Gastrointestinal-Nursing-Forum)

## Further reading/useful resources

Royal College of Nursing (2020) A Competency Framework for Rheumatology Nurses. Available at: [www.rcn.org.uk/professional-development/publications/pub-009004](http://www.rcn.org.uk/professional-development/publications/pub-009004)

NHS Education for Scotland (2021) Nursing, Midwifery and Allied Health Professions (NMAHP) Development Framework. Available at: [www.nmahpdevelopmentframework.nes.scot.nhs.uk](http://www.nmahpdevelopmentframework.nes.scot.nhs.uk)

Crohn's & Colitis UK Resources for Health Care Professionals available at: <https://crohnsandcolitis.org.uk/our-work/healthcare-professionals>

Royal College of General Practitioners IBD Toolkit available at: <https://elearning.rcgp.org.uk/course/view.php?id=702#:~:text=The%20toolkit%20provides%20tips%20to,supporting%20patients%20living%20with%20IBD.>

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## Glossary

6-MMP – 6-methylmercaptopurine

AHPs – allied health professionals

BSG – British Society of Gastroenterology

BSPGHAN – British Society of Paediatric Gastroenterology, Hepatology and Nutrition

CDAI – Crohn's Disease Activity Index

CRP – C-reactive protein

CT – computerised tomography scan

DEXA – Bone density scan (dual energy x-ray absorptiometry)

ECCO – European Crohn's and Colitis Organisation

ESPGHAN – European Society for Paediatric Gastroenterology Hepatology and Nutrition

Hb – haemoglobin

HBI – Harvey Bradshaw Index

IR(ME)R – Ionising Radiation (Medical Exposure) Regulations (2017)

LFTs – liver function tests

Mayo score – disease activity index for ulcerative colitis

MCV – mean corpuscular volume

MR – magnetic resonance scan

N-ECCO – Nurses-European Crohn's and Colitis Organisation

NICE – National Institute for Health and Care Excellence

PCDAI – Perianal Crohn's Disease Activity Index

PUCAI – Paediatric Ulcerative Colitis Activity Index

RCGP – Royal College of General Practitioners

SCCAI – Simple Clinical Colitis Activity Index

TDM – Therapeutic Drug Monitoring

TGN – Tioguanine Nucleotide levels

U&E – urea and electrolytes

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Byron C, Cornally N, Burton A and Savage E (2020) Challenges of living with and managing inflammatory bowel disease: A meta-synthesis of patients' experiences. *Journal of Clinical Nursing* 29(3-4), pp.305-319.

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## RCN quality assurance

### Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

### Description

This RCN professional practice framework for inflammatory bowel disease (IBD) clinical nurses specialists aims to clarify IBD advanced and specialist nursing roles at different levels and to support role development.

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