



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

CLINICAL PROFESSIONAL RESOURCE

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**FRAMEWORK FOR PROFESSIONAL PRACTICE FOR NURSES WORKING IN INFLAMMATORY BOWEL DISEASE IN ADULT AND PAEDIATRIC CARE SETTINGS**



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 largeeigeeed lir



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

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, Holbroivtrracen-GBë6.8 (o)-2.6 (s())Tj EMC ET EMC B



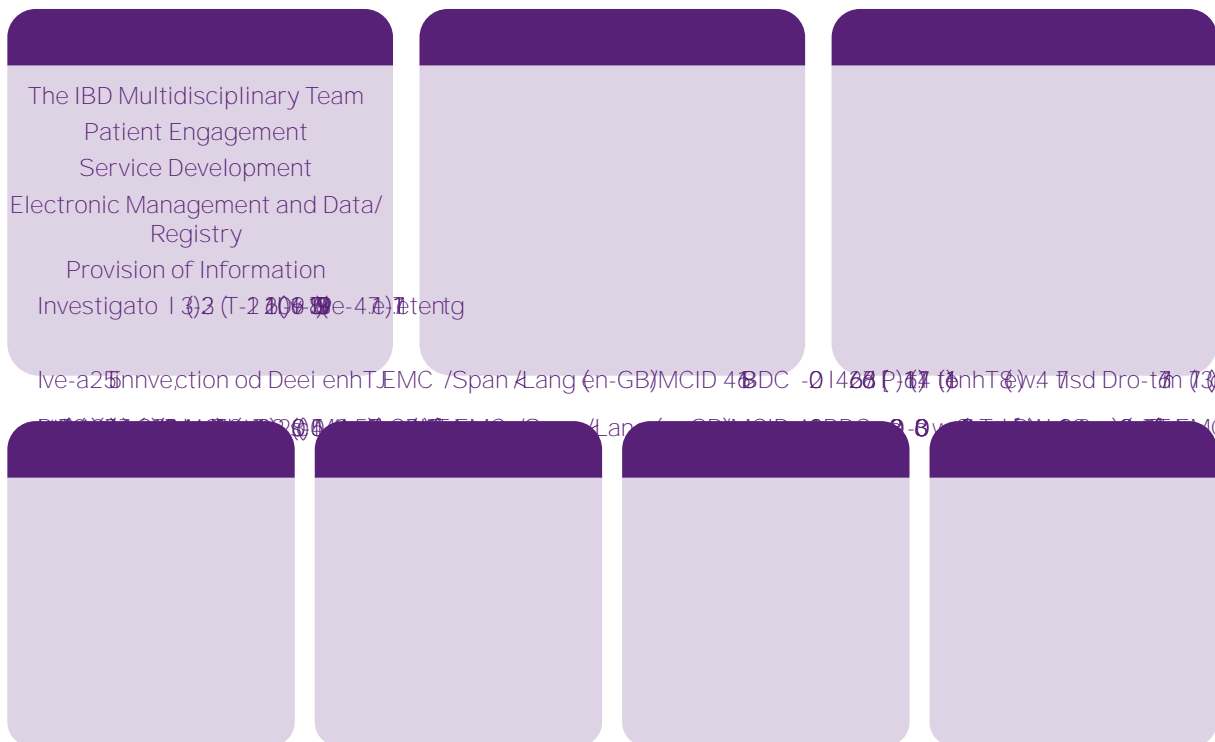
- IBD CNSs contributed a considerable amount of unpaid overtime (4.13 hours per week each on average) to cope with the needs of their patient population
- while almost half (43%) of IBD CNSs had a prescribing qualification, only 14% had a Master's degree in Advanced Practice, the current standard for 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 is a 50% increase on the current standard of 1.5 WTE per 250,000 population.

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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)













## Clinical practice

ENHANCED	ADVANCED	CONSULTANT
<p>On diagnosis of IBD, facilitates a full assessment of the patient's disease within their scope of practice.</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</li> </ul>		

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**ENHANCED**

- rationalising the modalities of investigations in informing the clinical assessment
- assessing delayed growth in children and adolescents; considering delayed puberty in adolescents
- completing and interpreting disease activity scores (for example, HBI, Mayo score, CDAI, SCCAI, PCDAI, PUCAI).

Assesses the psychological and social impact of diagnosis on the patient. This should consider:

- sexual function
- mental health
- employment/education
- relationships
- fatigue
- faecal incontinence

**ADVANCED****CONSULTANT**

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>		

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## Leadership

ENHANCED	ADVANCED	CONSULTANT
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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>



ENHANCED	ADVANCED	CONSULTANT

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## Evidence research and development

ENHANCED	ADVANCED	CONSULTANT



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>	

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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

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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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6-MMP – 6-methylmercaptopurine

AHPs – U4-22.6 (-3.8 (l)79.1 (i)7.6 (e)-3.7 h1 (e)1.7 (a)8.5 40u)5.8 (t)15.2 (t p)-1.8 (r)6.4 (l)35.4 (v)19 (e)-0.7

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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

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