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PRACTICE  
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# Paediatric Inflammatory Bowel Disease Clinical Nurse Specialist Competency Framework

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# Acknowledgements

The RCN wishes to thank everyone involved in the development of this competency framework.

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This document has been designed in collaboration with our members to ensure it meets most accessibility standards. However, if this does not fit your requirements, please contact [corporate.communications@rcn.org.uk](mailto:corporate.communications@rcn.org.uk)

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# Introduction

The number of children with inflammatory bowel disease (IBD) has risen significantly over the years (RCN, 2024), and therefore the need for increased paediatric IBD clinical nurse specialists has risen too. As a result of the increase in posts many nurses are new to the field, lone workers or establishing new services within existing gastroenterology departments. It must be acknowledged that not all paediatric nurses care solely for children with IBD, but a range of other gastroenterology conditions too.

Following the publication of the RCN's *Framework for Professional Practice for Nurses Working in Inflammatory Bowel Disease in Adult and Paediatric Care Settings* (Royal College of Nursing, 2024) a need was identified to have a tool linked to the framework to formalise the training and confidence building of new or developing paediatric nurses in post. This tool has been aligned with the RCN four pillars of nursing and can be used to support the professional or career development of paediatric nurses within existing gastroenterology teams.

Within the national RCN network for paediatric nurses working with IBD patients, a survey was conducted during the summer of 2024, to evaluate job roles/banding and self-assessed competencies. This survey identified a need for a competency document to improve standards. There is no formal training for this specialist role, and the survey demonstrated the relatively junior workforce and the discrepancy between the banding and the variation within services across the UK. The survey will be repeated following publication of these competencies to evaluate the effectiveness of the document in improving standards.

The purpose of this competency framework is to formalise the standards for paediatric nurses working in different roles related to IBD. It provides a solid foundation and encompasses some of the challenges and complexities associated with working in paediatrics.

This framework has been designed to allow flexibility within service development and allow both new and experienced nurses to demonstrate their progression and abilities. It is aimed at registered nurses who are working with paediatric patients with IBD. The aim of this document is to advance knowledge and skills for nurses working with paediatric IBD patients and who are expected to display professional standards of practice and behaviours required by the Nursing and Midwifery Council (NMC) (2018). These include:

- 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.

# Competency framework

## Scoring system

The scoring system for the competencies will be a level of achievement between 1-5.

1. New to the skill.
2. Unable to perform the skill safely, without supervision.
3. Can perform the skill safely with supervision.
4. Confident of knowledge and ability to perform the skill safely and independently.
5. Can teach knowledge and skills to others and can demonstrate initiative and adaptability to dynamically risk assess and respond to changing situations.

## Clinical practice

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
1. Recognises own level of ability and scope of practice, acknowledging limitations and referring to others where necessary.				
2. Has relevant skills and understanding of the administration of commonly used medicines in IBD, and can effectively communicate this with staff, patients and families.				
<p>3. Is able to facilitate a full assessment of the patient's disease, within their scope of practice. This may include:</p> <ul style="list-style-type: none"> <li>• demonstration of thorough history taking</li> <li>• completing and interpreting disease activity scores using the Paediatric Crohn's Disease Activity Index (PCDAI) and Paediatric Ulcerative Colitis Activity Index (PUCAI)</li> <li>• differentiating between Crohn's disease, ulcerative colitis and IBD unclassified</li> <li>• identifying phenotype, extent and severity of disease including GI complications such as stricture, perforation, fistulae</li> <li>• demonstrating disease mapping</li> <li>• assessing delayed growth and puberty in children and adolescents.</li> </ul>				

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
<p>4. Is able to assess and refer for extra-intestinal manifestations in IBD including:</p> <ul style="list-style-type: none"> <li>• bone health (including referral for DEXA scan if appropriate)</li> <li>• ocular disease</li> <li>• rheumatological disease</li> <li>• dermatological conditions</li> <li>• oral diseases</li> <li>• perianal disease</li> <li>• hepatology conditions.</li> </ul>				
<p>5. Assesses nutritional status of the patient and refers if appropriate.</p>				
<p>6. Assesses the psychological and social impact of IBD on the patient and refers appropriately if required. This may include but is not limited to:</p> <ul style="list-style-type: none"> <li>• mental health</li> <li>• education/employment</li> <li>• fatigue</li> <li>• faecal incontinence</li> <li>• pain</li> <li>• body image</li> <li>• relationships</li> <li>• sexual function</li> <li>• scars or stomas.</li> </ul>				

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
<p>7. Awareness and understanding of the potential complexities of patients with Very Early Onset IBD or Monogenic IBD, and ensures these are considered as part of individualised care.</p> <p>Potential complexities may include:</p> <ul style="list-style-type: none"> <li>• more aggressive disease</li> <li>• resistance to conventional therapies.</li> </ul>				
<p>8. Identify appropriate radiological tests, interpreting reports, and escalate accordingly within scope of practice.</p>				
<p>9. Applies knowledge of endoscopy procedures and can understand reports. Is able to discuss reports with patients, families and the MDT.</p>				
<p>10. Demonstrates ability to interpret frequently used blood and stool tests appropriate to clinical diagnosis. Is aware of the normal parameters and action to take when results are abnormal.</p>				
<p>11. Demonstrates ability to interpret therapeutic drug levels (TDMs), such as thioguanine (TGN) or biologics levels. Can identify need for escalation.</p>				
<p>12. Completes counselling and pre-screening prior to patient commencing on immunosuppressive medication and can provide rationale for this.</p>				
<p>13. Demonstrates comprehensive skills for developing personalised plans of care, using accredited and evidence-based guidelines and protocols.</p>				

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
14. Demonstrates ability to work as part of the MDT, in collaboration with other specialities and/or external agencies.				
15. Contributes to MDT discussions as a patient advocate.				
16. Has a good knowledge of the surgical procedures related to IBD and applies this knowledge to care planning and delivery post operatively.				
17. Completes training in, and has an understanding of local safeguarding policies, and is able to apply them and identify and escalate concerns appropriately.				
18. Undertakes complex conversations with patients/carers to inform of investigation results, diagnosis, complications, and treatment plans.				
19. Uses appropriate communication skills and is able to adapt these where necessary when providing education to patients and their families.				
20. Undertakes complex conversations and formulate treatment plans with patients and families when there is a difference of opinion related to treatment choices.				
21. Supports young people with understanding disease process and treatments to aid adherence to treatment as well as encouraging healthy lifestyle choices.				
22. Has awareness of available IBD support networks and ability to signpost families to these organisations.				

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
23. Has the ability to manage the IBD Advice Line (or equivalent), prioritising in a time appropriate manner, with an awareness of own knowledge and limitations and when to seek advice from senior colleagues.				
24. Is involved in the preparation and education of patients transferring from paediatric to adult IBD services.				
Action plan to achieve required competency level				

## Leadership

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
1. Proactively develops relationships within the IBD team and with patients/parents/carers, to encourage productive working.				
2. Actively participates in IBD nurse network groups.				
3. Contributes to quality improvement and service development.				
4. Requests feedback from colleagues and patients/families for service evaluation and development.				
5. Offers supervision and specialist expertise where appropriate.				
6. Acts as a positive role model for junior staff and other MDT colleagues.				
7. Identifies and raises risk issues within the IBD service and works within local organisational policies.				
8. Contributes to the IBD service operational policy and annual report.				
9. Participates in, and contributes to, regular clinical supervision of team members.				
10. Leads on co-ordinating care for complex patients and acts as an advocate for the patient/family.				
11. Has ability to act as lead, co-ordinating the safe transfer of patients to adult care.				
12. Assists in the implementation of digital change to improve delivery of care.				
Action plan to achieve required competency level				

## Facilitating education and learning

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
1. Demonstrates knowledge and understanding of gastrointestinal anatomy and physiology in health and disease.				
2. Demonstrates knowledge and understanding of the aetiology and pathophysiology of paediatric IBD.				
3. Can identify relevant local and national paediatric guidelines and implement appropriately.				
4. Demonstrates knowledge and understanding of the relevant pharmacology related to the drugs used in IBD, including methods of administration, mode of action and possible benefits and risks/ side-effects.				
5. Awareness of the use of unlicensed medications and the application of these in practice, including funding criteria and emerging treatments.				
6. Demonstrates knowledge and understanding of the use of nutrition as a treatment for paediatric IBD, and has an awareness of the various routes for administration.				
7. Demonstrates knowledge and understanding of the potential implications of disease on growth and development.				
8. Has knowledge and understanding of the extra-intestinal manifestations of IBD and their management.				
9. Is able to understand and articulate the mental health risks associated with IBD and knows how and where to escalate any concerns.				

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
10. Critically assesses own learning needs, seeking opportunities to develop knowledge and skills. This may include formal university education and/or using initiative to benefit from informal education.				
11. Understands the benefit of being involved in regional and national IBD networking and collaborations associated with IBD.				
12. Uses self-reflection and peer support to develop, rationalise and navigate higher-level of reasoning.				
13. Advocates for the patient by providing appropriate education to schools/colleges.				
14. Provides relevant education to ward staff/ junior staff in the hospital setting and facilitates/ participates in team teaching sessions.				
15. Provides relevant education and training for other healthcare settings including GPs.				
16. Contributes to the development of educational materials, relevant protocols and policies.				
17. Has an awareness of potential need for colorectal cancer screening (in line with BSG guidelines).				
18. Follows local or national pathways for transition of patients to adult care.				
Action Plan to achieve required competency level				

## Evidence, research and development

Competency statement	Level of achievement 1-5	Evidence to support practice	Mentor signature and date	Self-assessment
1. Regularly audits the IBD service and benchmarks practice against national IBD standards where appropriate.				
2. Keeps up to date on the research developments in IBD and critiques relevant papers and how they may apply in own clinical practice.				
3. Participates in IBD research activity where applicable.				
4. Has knowledge of the legislation and complexities around consent to participate in paediatric research, acknowledging the ethical considerations involved in consent/assent.				
5. Identifies areas within own practice where further research would be beneficial.				
6. Undertakes good clinical practice (NIHR) training where necessary.				
Action plan to achieve required competency level				

# Glossary

<b>BSG</b>	British Society of Gastroenterology
<b>DEXA</b>	Bone density scan (dual energy x-ray absorptiometry)
<b>GI</b>	Gastrointestinal
<b>MDT</b>	Multidisciplinary team
<b>NIHR</b>	National Institute of Health and Care Research
<b>PCDAI</b>	Perianal Crohn's Disease Activity Index
<b>PUCAI</b>	Paediatric Ulcerative Colitis Activity Index
<b>TDM</b>	Therapeutic drug monitoring
<b>TGN</b>	Tioguanine Nucleotide levels

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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

The number of children with inflammatory bowel disease (IBD) has risen significantly over the years and the need for increased paediatric IBD clinical nurse specialists has risen too. As a result of the increase in posts many nurses are new to the field, lone workers or establishing new services within existing gastroenterology departments. The purpose of these competencies is to formalise the standards for paediatric nurses working in different roles related to IBD and provide a solid foundation that encompasses some of the challenges and complexities associated with working in paediatrics.

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