



Crohn's & Colitis UK Nursing Programme Report

2023

ABOUT OUR NURSING PROGRAMME

The IBD Nursing Programme was launched as a five-year plan in May 2019, setting out our ambition to build a community of Crohn's & Colitis UK Nurse Specialists, to make a positive difference to people's lives. The role of an IBD Nurse Specialist is essential for patients with Crohn's and Colitis. They are responsible for leading services and managing a caseload of patients, as well as providing diagnoses, care planning, treatment, follow-up and continuity of care as a core part of the IBD team. People with Crohn's and Colitis tell us that having access to an IBD Nurse Specialist is a lifeline for them. Ultimately, we believe that every Crohn's or Colitis patient should expect to have access to a suitably qualified IBD nurse specialist to receive high quality IBD care, which is currently not the case³.

To join the programme, IBD nurse specialists need to meet a clear person specification and application process and in return receive funding for either a MSc in Advanced Clinical Practice (ACP) or, for those already holding MSc ACP, they can join the Royal College of Nursing (RCN) Advanced Nurse Practitioner (ANP) credentialing programme. Nurses who join the Programme also attend four community days each year, led by Crohn's & Colitis UK, (currently three virtual and one in person). Through these community days they share learning outcomes to deliver the charity strategy in their services, obtain peer support as they develop and participate in a buddying scheme.



"We provide peer support, help them to analyse their current service and set learning outcomes for improvement."

Isobel Mason, Nurse Consultant at Crohn's & Colitis UK

Once the nurses join the programme, they become a Crohn's & Colitis UK badged nurse, identifiable by their purple Crohn's & Colitis UK lanyard.

Nurses working at this level will develop and maintain the ability to carry out advanced assessment, prescribe medication, monitor patients independently and significantly improve patient pathways and health outcomes. The nurses work to a role description ensuring that the Charity's strategies are embedded in clinical practice and are visible in hospital care.

Hannah, was diagnosed with Crohn's Disease in 2007

"IBD nurses are a literal lifeline for me and have been since I was diagnosed with Crohn's in 2007. I know that I can always go to my IBD nurse for help, and even though it's not instant, I KNOW without doubt that she will get back to me. My IBD nurse is my insider, someone who has gotten to know me personally, and fights internally to make sure I get the care I need. My IBD nurse is a vital part of my care, saving me from so many unnecessary trips to the GP, my gastro consultant and A&E. Everyone with IBD deserves their own IBD nurse like Lisa."

WHERE WE ARE TO DATE

We now have 34 nurses participating in the Nursing Programme, 21 on the RCN pathway and 13 on the MSc pathway. Of those in the original cohorts (2019 and 2021), six nurses have so far successfully completed their MSc, all of whom have moved on to the credentialing pathway. [It can take up to three years to complete the part-time MSc]. Of those who enrolled as part of the credentialing pathway, seven nurses have successfully credentialled with RCN and are recognised as Inflammatory Bowel Disease (IBD) Advanced Nurse Practitioners.

Four nurses have withdrawn from programme since its inception in 2019. One nurse left as she retired from being an IBD Nurse Specialist, but she has remained connected to the programme through a volunteer role helping to support the programme nurses. This year (2024) we aim to recruit a further five nurses to the MSc pathway and up to 10 nurses to the credentialling pathway.

For more information about the current Crohn's & Colitis UK nurse specialists [click here](#).



“RCN Credentialling gives nurses formal recognition of their advanced level of expertise. We have worked together with Crohn's & Colitis UK to ensure IBD nurse specialists can demonstrate their skills in clinical practice, leadership, education, and research to colleagues, employers, patients, and the public - by developing the first ever specialist credentialling pathway.

Crohn's & Colitis UK will continue to support nurse specialists as they use their expertise, advanced practice, leadership, and education to support people living with Crohn's and Colitis. Through sharing best nursing practice and giving access to charity resources and support, we can give our nurses the skills, knowledge, and resources to ensure high-quality, sustainable IBD care.”

Wendy Preston, Head of Nursing Practice, Royal College of Nursing

NURSING PROGRAMME EVALUATION 2023

In order to understand the impact of the nursing programme, nurses were asked to complete a question-based evaluation form. This incorporated questions from the 'Foundation of Nursing Studies' model of personal and professional impact evaluation to understand the impact on nurses of participating in the programme, the impact on their own IBD service and on patient care.

Examples of learning outcomes and impacts reported by nurses included:

- Setting up a virtual self-management review service
- Introduction of nurse delivered flare clinics utilising clinical skills obtained through completing the ACP MSc
- Greater awareness and involvement in research relating to IBD and quality of life
- Implementation and evaluation of personalised care plans undertaken as an MSc dissertation project
- Business case development to increase resources and improve access for patients.

We conducted in depth interviews with a smaller number of the programme nurses from both the MSc and credentialling pathways. We used a modified version of the Kirkpatrick evaluation model to find out more about their experiences and impact of their learning while on the programme.

Interviewees were asked to feedback on Reactions, Learning, Behaviour, and Results relating to their involvement in the nursing programme and relating to their learning outcomes and impacts on patients.

In addition to individual IBD service feedback - nurses were asked to feedback on the programme itself, what worked well and what could be improved. Feedback suggested face-to-face community days were more productive, however there were logistical challenges in terms of travel and cost for the nurses despite having a Memorandum of Understanding signed by their managers, so virtual days were appreciated. The strength of community among the nurses on the programme was commented on by all with the opportunity to keep in touch with each other in between community days felt to be motivational and supportive.

These case studies are included below.

CASE STUDIES

Gayle Martin, Ulster Hospital, MSc pathway (Joined 2021)



"I was unable to get approval to do the MSc ANP through my Hospital Trust because I work part-time. I am delighted that the funding from Crohn's & Colitis UK has enabled me to go ahead. The support helps me feel as though I'm not on my own.

Through the community days I get ideas that I haven't thought about from like-minded people - having that knowledge and support is priceless.

Since commencing the MSc, patients are receiving a more efficient service, as my colleague will now discuss patient issues with me, we chat through the options and come up with a plan. Previously, she would have emailed a consultant, and they maybe wouldn't have been able to get back to her straight away, therefore delaying patient treatment or advice.

Medical and surgical colleagues will accept referrals directly from me now, trusting that I have assessed the patient and run appropriate investigations.

We have a 'gastro hub' where we take referrals from GP's, emergency care settings and other specialties within the hospital for patients with suspect IBD. They used to see a consultant first and were sent through to the IBD nurse once diagnosed. Now referrals for patients with suspected IBD are also being sent directly to me.

I can usually see them within 48 hours and request investigations, getting them on to rapid access scope lists, diagnosed and onto treatment a lot quicker. This initiative is improving the waiting times for the rest of the consultant clinics so they can meet other targets, as they can therefore see patients with other gastro issues.

Prior to the development of the Gastro Hub and rapid access clinics, it took at least three months to see a consultant, whereas now patients can be seen within a week.

I was able to set up 'The IBD Clinical Nurse Specialist (CNS) Rapid Access Clinic', and see patients who don't yet have a diagnosis, only because I am undertaking the MSc."

Natalia Fumis, University Hospital Llandough, RCN Credentiaing Pathway (Joined 2021)

"The support from the programme is immense. It's hard to quantify it and how much it's helped me. It's just opened up so much to me, in ways of support, but also knowledge, encouragement, and information. I've gone from just caring for patients and treating their IBD to that next step, being much more aware of the quality of care that is delivered and meeting standards.



I don't think I really appreciated the role that I played in early diagnosis, and how that can impact on a patient's outcome and their future.

Since joining the Programme, I've developed, from nothing, a virtual self-management programme that works across both sister hospitals. We've got a database now that follows all our stable, well patients who are either not on any regular medication or taking mesalazine. We monitor them virtually and as a result, have taken hundreds of patients out of unnecessary clinic appointments.

What's really good is that because you're reviewing them and patients have a plan, if they're unwell, they've got quick access back into the service, so they're being seen at the right time. It's patient-centred care, there for when they need it, not for when you've got this routine annual appointment.

Taking out some of these routine appointments has freed up clinic appointments for new patients. We've got such a lot of new patients diagnosed with colitis that are sat waiting to be seen, and this project helps with that."

Cara Crisp Scunthorpe General Hospital, MSc pathway (joined 2019)



“When I first started working as an IBD nurse, I was overwhelmed by the complexity of the speciality. The clinical dilemmas that accompany complex cases and the holistic disease burden that patients deal with socially and psychologically was hard to grasp. I then became aware of the campaign from Crohn’s and Colitis UK ‘every patient should have access to a suitably qualified IBD nurse’ and I thought I have got to do this, if this is the career I want to be in, I need to be able to provide the level of advice and care that

IBD patients require. As a result of the MSc and the programme, my practice and knowledge has improved allowing me to provide the best care possible. Following the course, the way I approach individual cases changed and I gained the ability to delve into case reports and research studies to look at treatment options and then present the findings to my consultant colleagues. This is something I would not have felt confident to do prior to the MSc.

The academic study and peer support from the Crohn’s and Colitis Cohort empowered me to be able to make changes and improvements within the service.

For example, I had identified a long time ago that a main priority for the service and part of the IBD standards was having a dedicated IBD Multi-Disciplinary Team (MDT). The programme gave me the confidence and skills needed to approach this challenge and find a solution that worked for all the team. We have now been part of dedicated IBD MDT since October 2023 that is working well and has improved the outcomes for our IBD patients. It has also proven to provide great learning opportunities for the IBD team.

The IBD Nursing Programme has also sparked my interest in research. I enjoyed completing the MSc Research project and compiling the findings for my dissertation. Research was an area that I had previously steered away from, fearful that it was too time consuming and intensive. I also thought it would be hard recruiting patients and had the belief that patients had enough to deal with without being enrolled in research. I couldn’t believe how wrong I was about this.

Our service has enrolled to participate in the Gondomar study, which is looking at the best care for patients with perianal fistulas. As a team we have really enjoyed our involvement so far and the reaction from our local population of patients has been positive. One patient enrolled on the trial said to me that it helps them get through the bad days, knowing that they’re being part of something much bigger that will benefit people in the future.”

Kerry Robinson, Royal Hallamshire Hospital, Sheffield, MSc pathway (joined 2021)

“I had struggled to get funding for my MSc for years, and I just couldn’t get any support from my Trust. The funding from Crohn’s & Colitis UK has allowed me to go ahead with the degree.

I’ve been working at an advanced practice level for a long time. But the MSc has still been really useful. I do really wish I’d done it a long time ago. The lack of funding for

continuing professional development is frustrating - there’s a lack of clarity about professional development funding and whether we can even access any of it. All I can get funding for at the minute for nurses in my team is level 7 prescribing. It feels they will only fund those courses they get a direct benefit from. It feels very, very short sighted when leadership, research and teaching courses improve practice. We need a clear development pathway, and this is something I would really like to champion.

*As part of my MSc, I did a module on teaching. I had to plan, deliver, and evaluate a teaching session for the course assessment so delivered a workshop at a national IBD nurse study day. The workshop was well evaluated, and I successfully passed the assessment/module. **This has given me more confidence in sharing my knowledge with more junior team members so patients will benefit from a better educated and skilled team of nurses.”***



Lucy Aitchison, Southport and Ormskirk Hospital, Mersey, and West Lancashire NHS Trust, MSc pathway (joined 2019)



"I'd been in post for about a year and wanted to improve my knowledge and skills further, so when I saw the opportunity to be able to do my MSc with Crohn's & Colitis UK it was perfect timing. What I didn't realise, was that alongside the MSc I'd get all of the networking and the peer support and everything else that goes along with the course, which was invaluable. I'm super proud to be a Crohn's & Colitis UK nurse specialist.

My increased knowledge and skills in clinical examination and diagnostics directly impacts patients on a day-to-day basis. Being able to prescribe, complete an episode of care and give full care to a patient within a clinic or within a telephone review, you know you're directly impacting patients care. I'm able to provide a more rounded service so patients aren't waiting, they're not having to have any delay to their treatment or coordination of care.

Completing the MSc has improved my ability to communicate in MDTs and be able to voice my concerns. I feel listened to, respected, and able to advocate for patients. One of my consultants who is the lead gastroenterology consultant for the hospital recently said to me 'I see you being a nurse consultant' which is a very big compliment.

For my dissertation I chose to do some work with Sheffield Hospital to look into personalised care planning and to trial implementing a personalised care plan into patients' routine review. Over a six-week period I sent out 40 care plans to patients, and out of those, 20 agreed to have the care plan implemented which was great. It was more of a fact-finding project than a full implementation because we wanted to find out if it's useful to patients and whether it was feasible for us to be able to implement on a wider scale and what setting it may be useful for. We also wanted to know if the care plan fits what patients want and whether the information was useful to them. If we decide to continue with the project as a team, it has given some good insight into personalised care planning and we have some better information to work from.

I'm planning to present my findings in our IBD audit meeting, to our consultants and will be disseminating the results to colleagues.

Rachel Campbell, Stepping Hill Hospital, Stockport, RCN Credentialing Pathway (joined 2019)

"I really wanted to do something to prove my worth to the Trust. They have a lot of Advanced Clinical Practitioners in emergency care and different places, but for specialist roles like IBD nursing, it's only just coming through. I wanted to be one of those pioneering people that shows they are doing an advanced role. I'm working at an advanced level, and I want it recognised.



When I've got my lanyard and badge on (which I wore when I went to the House of Commons) patients notice that I'm a Crohn's & Colitis UK nurse specialist. I think that is a really special thing that leads to really positive conversations with patients because it's visible. I've got it around my neck, I've got my badge on, and they can see that's what I am. It's on my sign off on my letters too.

It's important that the patients have that link. Probably, more come into the to the charity and are signing up because they've realised that they need that support. Social media has helped that too as the charity has built up the Facebook page and the Twitter page etc. I think patients will talk about it more now.

Post-pandemic, we had to adapt the service to enable us to see patients flaring very quickly. The HOTIBD clinic was set up really quickly and carried on throughout the pandemic, seeing people face to face. I also felt that it was important that that we carried on having a hot clinic face to face and to try and keep people out of A&E. The HOTIBD clinic has improved patient experience and satisfaction with compliments having been sent to the trust. It's also meant fewer patients requiring emergency department visits or admissions with potential savings around £44K."

PUBLICATIONS AND VIDEOS

¹Younge L, et al. Frontline Gastroenterology 2020;0:1-6. doi:10.1136/flgastro-2019-101354 [Specialist inflammatory bowel disease nursing in the UK: current situation and future proofing \(bmj.com\)](#)

²Royal College of Nursing 2022 <https://www.rcn.org.uk/news-and-events/Blogs/recognising-specialist-practice-through-credentialing-inflammatory-bowel-disease>

³Crohn's & Colitis UK Nurse Audit Report 2023: <https://s3.eu-west-2.amazonaws.com/sr-crohns-craft/documents/c-cuk-audit-report-3pp-a4-final.pdf>

⁴A day in the life of an IBD nurse (video) <https://www.youtube.com/watch?v=logNMgLMGc4>

⁵Ainley R, Mason I, Parekh A, Younge L, Woo N (2024) 'More IBD nurses, Better Care' - A collaborative approach to driving inflammatory bowel disease nursing development. Gastrointestinal nursing 22(3) 142-143. <https://www.magonlinelibrary.com/doi/abs/10.12968/gasn.2024.22.3.142?journalCode=gasn>

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