

## Inflammatory Bowel Disease Nurse Specialists, National Workforce Audit 2023

### Summary

Results from our audit of IBD Nurse Specialists has shown that IBD nurse specialists are increasingly focused on IBD-specific care compared with our last audit in 2019<sup>1</sup>. Fewer IBD Nurse Specialists were covering other areas such as general gastroenterology and endoscopy. Nearly 50% of those surveyed were still early in their IBD Nurse Specialist career, having been in the role for less than 5 years, with only 20% overall having been educated to masters level.

Although the results were indicative of an increase in nurse numbers since the 2019 audit, there is still need for improvement with issues reported around recruitment and retention. Only an estimated one third of services meet the nationally agreed standard of 2.5 nurses per 250,000 of population<sup>2</sup> (with a caseload of 500 patients per nurse). The data upon which the nationally agreed standard was developed is based on lower prevalence data than we have now so it is likely that the caseload for individual nurses has increased, impacting the service that can be provided.

### The importance of IBD Nurse Specialists

The availability of IBD Nurse Specialists across the UK is vital for people living with IBD to be able to access responsive health services and improved clinical outcomes. IBD Nurse Specialists play a fundamental role in delivering high quality patient care and experience, lead patient centred service redesign, improve the quality of care and represent excellent value for money. Where people living with IBD report having contact with an IBD nurse specialist, they are more likely to have the information and skills to manage their condition<sup>3</sup>.



We know that people living with IBD can have complex care needs<sup>4</sup> and IBD Nurse Specialists are central to their care. They need to be able to practice independently, supporting patients by making complex decisions around treatment as part of the multi-disciplinary team. To do this effectively, nurses need to be suitably trained, ideally to masters level, with a masters in advanced clinical practice. Crohn's & Colitis UK supports IBD Nurse Specialists to complete a masters in advanced clinical practice helping to increase the number of suitably trained nurses in the UK.

### The nurse audit

The purpose of the audit was to give us an up-to-date picture of the IBD nursing workforce across both adult and paediatric services in the UK. We wanted to understand if the number of IBD Nurse Specialists was still increasing, and if so, were services meeting the recommended minimum standard. We know that the NHS and its workforce is under pressure and facing challenges, with the effects of the COVID-19 pandemic still being felt. We asked about some of these challenges so we could understand where the pressures lie.

The audit was carried out using a two-part survey. The first part for all nurses to complete asking about their own background and experiences. The second part was for lead nurses to tell us about their service.

- 1 [Younge L, Mason I, Kapasi R. Specialist inflammatory bowel disease nursing in the UK: current situation and future proofing. Frontline Gastroenterology 2021;12:169-174](#)
- 2 [Alison Leary et al. Modelling the Inflammatory Bowel Disease Specialist Nurse Workforce Standards by Determination of Optimum Caseloads in the UK. Journal of Crohn's and Colitis 2018;12\(11\): 1295-1301](#)
- 3 [Crohn's and Colitis Care in the UK – The hidden cost and a vision for change](#)
- 4 [British Society of Gastroenterology: The Developing Role of the Inflammatory Bowel Disease \(IBD\) Nurse in supporting people living with Complex IBD](#)

## Who responded to our audit?

The survey was open from 24 November 2022 to 15 January 2023 and generated responses from 299 nurses across 151 services (66%, based on the 2019 list of IBD services from IBD UK). Responses came from all 4 UK Nations with 87% of respondents working in adult services, 9% in paediatric services and 4% across both.

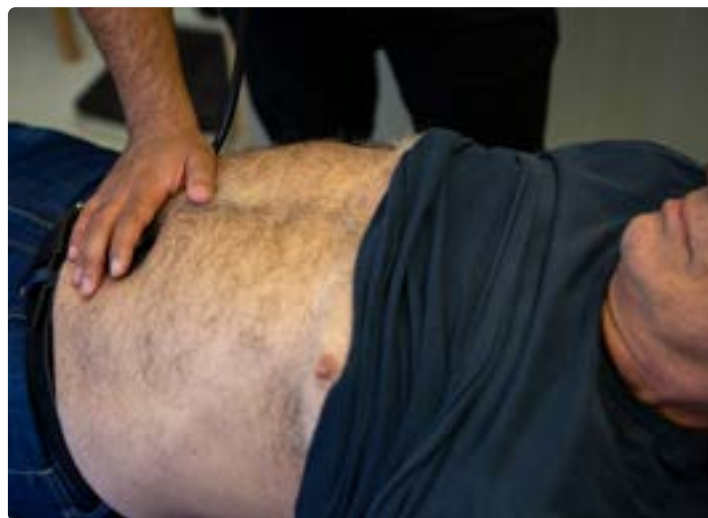
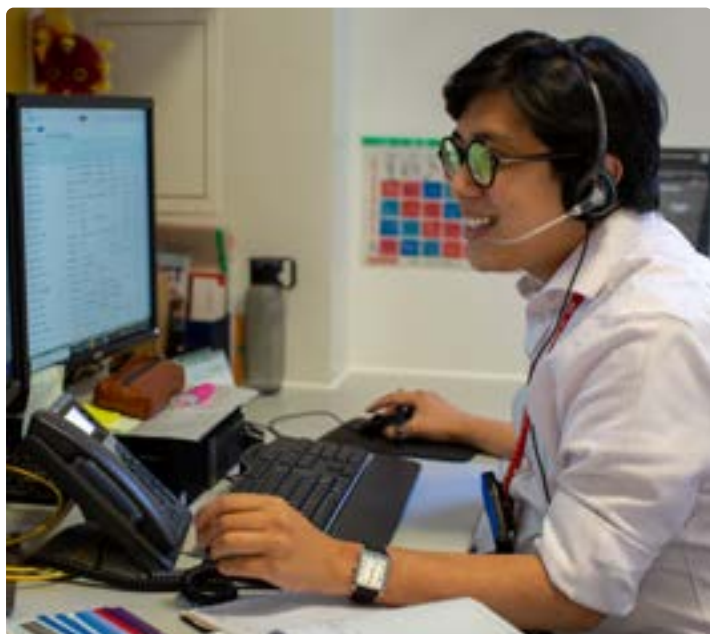
England	Northern Ireland	Scotland	Wales
250 (84%)	14 (5%)	17 (5.5%)	18 (6%)

We found that nearly half (46%) of the nurses who responded had been working in IBD Nurse Specialist roles for less than 5 years, meaning they are still early in their careers in IBD Specialist Nursing. This means that within IBD nursing, less experienced nurses are expected to provide for complicated care needs. Only one in five were educated to masters degree level and only 8% had a masters degree in advanced clinical practice.

Since our last audit in 2019, IBD Nurse Specialists have reported that they are spending more time focused on IBD and less time working across other areas such as general gastroenterology or endoscopy.

## A workforce under pressure

The last three years have been incredibly difficult for the NHS with the COVID-19 pandemic putting additional strain on an already strained system. We know that IBD services are still feeling the effects of the pandemic with many who responded telling us there are longer waits for outpatient appointments and surveillance colonoscopies as well as longer waits in the diagnostic pathways for IBD.



7 in 10 services told us that they have administrative support. Despite this, 9 in 10 services told us that IBD Nurse Specialists are still carrying out administrative work such as booking appointments and responding to non-clinical queries, that could be delegated elsewhere.

Nearly all the nurses that we surveyed (95%) told us their role involves managing or running the IBD advice line, however only 30% had received formal training on running such a service. While still a low number, it represents an increase from the previous survey in 2019 and can be partly attributed to the Advice Line Training offered by Crohn's & Colitis UK. We know this is an area of work that IBD Nurse Specialists find particularly stressful, with just under half of those who responded (42%) rating their stress levels associated with advice line provision as high. Advice lines are vital in helping those living with IBD to manage their condition and in particular when experiencing a flare, reducing the need for urgent care through enabling prompt and appropriate action to manage and treat it<sup>5</sup>. Crohn's & Colitis UK are helping by providing advice line training for IBD nurse specialists ensuring they have the support they need to run this vital service.



IBD Nurse Specialists are feeling pressure from the stresses of their role. One quarter of the nurses we surveyed told us that they were thinking of leaving their job, with the figure even higher in Scotland at just over one third. They told us that they are feeling exhausted (50%), undervalued (49%) and are under too much pressure (46%). This is similar to the results reported in the 2022 NHS Staff survey<sup>6</sup> where nearly 40% of registered nurses and midwives described feeling burnout due to their work, and a quarter of all NHS staff surveyed said they will probably look for a job at a new organisation in the next 12 months.

Nearly 1 in 5 (18%) of the services who responded to the survey told us they had vacancies, and more than half of those were finding those vacancies difficult to fill. Recruiting and retaining appropriately trained IBD Nurse Specialists is crucial in providing and maintaining high quality care. There should be clearly defined career pathways for all grades of nurses working within IBD care, with sufficient resourcing for all IBD Nurse Specialists to hold, or work towards, masters level nursing qualifications, to retain high calibre nurses and encourage more into the profession.

We've been working with the Royal College of Nursing on a career framework for IBD Nurse Specialists which is due to be published in early 2024. It clearly defines the knowledge and skills demonstrated at different levels of nursing practice, supporting career development and progression for IBD Nurse Specialists.

## Change for the better

Our last audit in 2019 showed that numbers of nurses were increasing, in part due to the Charity's 'More IBD Nurses–Better Care' campaign which was launched in 2016. This time, 45% of services told us that they'd had an increase in IBD Specialist nursing provision, suggesting that the numbers are likely to be still increasing. However, we know there are still too few IBD Nurse Specialists overall and accessing adequate training, in the form of a masters degree, is still difficult for many.

In 2019, only 14% of services were meeting the minimum standard of 2.5 nurses per 250,000 population<sup>5</sup>. The 2023 IBD UK Benchmarking survey results will be launched in 2024 and will tell us how many services are now meeting the IBD Standards, including for whole time equivalent nursing posts. From our audit we estimate around one third are now meeting the standard.

Patients who have access to an IBD Nurse Specialist are more likely to be able to manage their condition, stay well for longer and stay out of A&E<sup>7,8</sup>. However we know, from a range of sources and from the calls that are made to our Helpline, that people living with IBD are still having difficulty accessing services including IBD Nurse Specialists. We also know that there has been a rise in the prevalence of IBD following a report carried out by Nottingham University<sup>9</sup>. This report from 2022 estimates there are currently over 500,000 people living with IBD – nearly double the previously estimated figure. Given the national standard of 2.5 nurses per 250,000 population was based on a lower prevalence figure and assumes a caseload per nurse of 500 patients, it seems likely that the caseload for individual nurses has increased and the numbers of nurses is simply not sufficient to meet demand.

In summary, although there are some positives to take from the audit results, we know there's still a long way to go to make sure everyone has access to a suitably trained IBD Nurse Specialist.

6 [2022 NHS Staff Survey Briefing](#)

7 [C Martinez-Vinson et al. Effects of introduction of an inflammatory bowel disease nurse position on healthcare use. BMJ Open. 2020;10:e036929.](#)

8 [P Leach et al. The effect of an inflammatory bowel disease nurse position on service delivery. J Crohns Colitis. 2014;8\(5\):370-4.](#)

9 [Crohn's & Colitis UK: Epidemiology Summary: Incidence and Prevalence of IBD in the United Kingdom](#)