



Original Article

Modelling the Inflammatory Bowel Disease Specialist Nurse Workforce Standards by Determination of Optimum Caseloads in the UK

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Abstract

Background and Aims: Crohn's disease and ulcerative colitis are the most common forms of inflammatory bowel disease [IBD], affecting 1 in 250 of the population in the UK. It is accepted that access to a specialist nurse service improves patient experience and outcome. National *Standards for the Healthcare of People Who Have Inflammatory Bowel Disease* [2013] defined the number of nurse specialists required at 1.5 full time equivalent per 250 000 population. The aim of this study was to determine if these standards were being met and to publish a new, robust, validated standard optimising the UK nursing workforce model.

Methods: Existing national data and specific workload and service data were collected from 164 IBD specialist nurses who completed a questionnaire designed to collect information on activity and complexity of work both done and undone.

Results: Data were received from all of the UK; 36% of respondents were specialist nurses in the field for 3 years or less. A higher caseload than the recommended level was reported by 63% of respondents. Unpaid overtime was regularly carried out by 84% of respondents. The IBD specialist nurse was involved in all areas of the patient pathway. Areas of work left undone were psychological interventions, prescribing medicines and physical assessments.

Conclusions: Compared with other specialties, IBD specialist nurses are less experienced. It is recommended that the current standard be increased to 2.5 full time equivalent specialist nurses per 250 000 patients, to mitigate the increasing complexity of the role, care and the 'rookie' factor.

Key Words: Inflammatory bowel disease; specialist nurse; workforce modelling

1. Introduction

One of the most important challenges for the NHS in the UK and health care worldwide is to accurately calculate both the expertise and the amount of time nurses require to care for different patient groups in a variety of environments. It is difficult to do this because nursing, in common with many human activities, is complex^{1,2} and dynamic. As a result, clarity over which information is even relevant to a proposed model may be challenging.³ Despite the complexity of nursing work, most approaches to examining the issue of nursing

resource are deterministic in nature and involve variations of time and motion models in which time is filled with a linear series of tasks.⁴

The two most common forms of inflammatory bowel disease [IBD] in the UK are Crohn's disease and ulcerative colitis which, taken together, affect around 1 in 250 of the population.⁵ IBD is currently a lifelong condition as there is so far no cure. Half of all newly diagnosed patients will be in their teens and twenties.⁵

It is widely accepted that access to effective IBD nurse specialist [NS] services improves experience and clinical outcomes for

patients.⁶ Patients often describe their IBD NS service as a lifeline. The national *Standards for the Healthcare of People Who Have Inflammatory Bowel Disease*⁷ first defined the numbers of NS required as 1.5 full time equivalent [FTE] per 250 000 population. The current national standards have been influential in increasing nursing numbers⁷; however, they were a result of consensus rather than evidence, and do not reflect the complexity of NS work.

Specialist nursing work varies in the UK. The levels of practice and the job title, for example, are not a reliable proxies for complexity of practice.⁸ This means that NS in the UK tend to work at a range of levels of complexity, offer a different range of interventions, and do so within many different service arrangements. These factors can affect workload burden. Other factors include complexity of patient needs⁹ and access to members of the multidisciplinary team¹⁰ [MDT].

In the UK, the role of specialist IBD nurses was described by the Royal College of Nursing in 2007 when providing guidance to development of best practice and local service organisation. The report outlines a number of knowledge and skills frameworks in a number of areas such as specialist knowledge, education, service development, management, and leadership. The scope of practice of the role includes areas such as telephone advice lines, rapid access clinics, follow-up clinics, inpatient care, managing an immunotherapy service, and administering and monitoring therapies.⁶

In countries outside the UK, the role of nurses in caring for patients with IBD varies across Europe and the rest of the world. A variety of systems of delivering care and differing levels of responsibility for nurses exist.¹¹ In 2018, N-ECCO produced a second consensus statement on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis, which made a number of statements regarding the role of the IBD nurse based on 'ideal' standards of care.¹²

As in many areas of health care, the workforce is modelled from the supply side rather than demand. Very little demand modelling can be found. In order to model a future UK IBD nursing workforce, demand modelling is needed to understand the need for the IBD nursing interventions. This includes understanding how the current workforce meets demand, what work is left undone, how much overtime [paid and unpaid] is required to meet demand, and the available skill mix in terms of complexity.

The aim of this study was to determine if the national IBD standards for IBD NS were being met, and to model the UK IBD nursing workforce.

2. Methods and data collection

2.1 A priori dataset complexity and factors that affect workload

A curated dataset of around 70 million hours of advanced practice specialist work carried out by approximately 18 000 nurses since 2009 was accessed to look at patterns and workload of other specialists working in long-term conditions. These data reflect varying levels of complexity of work and have generated indicators of workload in order to use stochastic approaches to optimum caseload calculation. From this curated dataset, a number of common factors which typically influence NS workload were determined. Examples of such factors include relationships with other members of the multidisciplinary team,¹⁰ complexity of caseload,¹³ access to administrative assistance,¹⁴ access to other services,¹⁵ and education and experience.¹⁶ To enable NS to make independent decisions rather than 'door-hang' for the decisions of others, issues such as access to non-medical prescribing¹⁷ and the ability to independently request investigations were also significant factors.

2.2 Consensus workshop of expert opinion: checking the assumptions

In order to use the existing a priori dataset and the online data collection tool, it was necessary to check the assumptions made regarding the workload and activity of this group. A consensus workshop of 15 IBD NS from across the UK was convened to check and challenge assumptions drawn from the dataset. The nurses were asked to explain their work in detail. Areas examined included the work environment, physical and psychological domains, social issues, case management, administration, and work left undone. The IBD NS had a work pattern similar to those in other long-term conditions such as multiple sclerosis and rheumatology.

2.3 Data collection specific to IBD

National data, from the IBD audit⁶ regional data from Crohn's and Colitis UK on current workforce¹⁸ and from population data on the incidence of IBD,¹⁹ were used to model demand initially. A 24-item questionnaire, exploring demographic data, caseload, and workload, was developed for this population by consensus, using clinical, patient, and academic experts based on a previously employed national study.¹⁰ The questionnaire was designed to gather data on activity and complexity of specialist nursing services provided, including work left undone, and used a format similar to the national optimum caseload modelling project.¹⁵ This was transferred to an online survey tool [administered using a Survey Monkey secure account]. The survey link was distributed through the Royal College of Nursing [RCN] IBD Nursing Network and other professional mailing lists during February 2017; 164 participants responded to the questionnaire. A single response only could be submitted from each computer. Analysis of the survey took place in March 2017.

2.4 Data analysis

Data were exported into Excel and modelled using descriptive statistics, for example demographics, pay band and length of service, workload, interventions delivered, work left undone, and educational background. Free-text comments were analysed using thematic content analysis.²⁰ Thematic content analysis is the approach best suited to free text questions in an otherwise quantitative questionnaire, as it does not rely on interpretation of data but instead reflects a 'low hovering over the data'.

2.5 Caseload calculations

Responses to the Survey Monkey workload questionnaire were received from 164 nurses who completed the questionnaire in whole or in part. The total population of NS in the UK is around 300 by headcount [FTE is unknown], so this equates to a 55% response rate.

3. Results

3.1 Respondent's demographic data and epidemiology of IBD in the UK

The country of practice, number of hospital sites covered, length of time working with IBD patients, patient population, area of IBD practice, and educational qualifications are summarised in [Table 1](#).

3.2 Time spent providing care for IBD patients

To determine how much of their time was spent caring for IBD patients, respondents were asked to estimate the percentage of working time they spent providing care for IBD patients. In all, 31% [51/164] of respondents spent 100% of their time caring for IBD

Table 1. Respondents' background characteristics.

Country of Practice ^a				
England	Wales	Scotland	Northern Ireland	
76% [124/164]	8% [13/164]	12% [20/164]	2% [3/164]	
Number of hospital sites covered ^b				
One	Two	Three	Four	Five plus
60%	25%	8%	5%	2%
Length of time working with IBD patients				
1 year	1 to 3 years	4 to 6 years	7 to 10 years	< 10 years
9% [14/164]	29% [47/146]	14% [23/146]	16% [27/146]	32% [53/164]
Patient population of IBD practice				
Adult	Paediatrics	Adult and transition	Paediatric and transition	Adult and paediatric
29% [48/164]	6% [10/164]	51% [84/164]	12% [20/164]	1% [2/164]
Area of IBD practice				
IBD	Mixed ^c	Stoma care	Other	
90%	8%	1%	1%	
Respondents' qualifications				
RGN	RN degree	RN diploma	Prescribing qualification	
58%	35%	28%	43%	

IBD, inflammatory bowel disease.

^a2% of respondents opted for 'Other'.

^bHospital sites were taken to include all types of hospital such as acute, community, etc.

^cMixed practice included areas such as IBD, surgery, research/clinical trials, infusion, stoma care, nutrition, hepatology, and nurse endoscopy.

patients; 51% [83/164] spent 80% of their time; 14% [23/164] 50% of their time; and 4% [7/164] 30% of their time. No respondents spent less than 30% of their time working with IBD patients.

3.3 Contracted hours of work

Respondents were asked to state their contracted hours of work. Totals of: 72% of respondents were contracted to work 36–37.5 h per week; 9% worked 26–30 h; 6% worked 21–25 h; 6% >37.5 h; 4% 31–35 h; 2% 7.5–15 h; 1% 16–20 h. In total this represents approximately 149 FTE for the 161 respondents to this question.

3.4 Unpaid overtime worked per week

To ascertain how much unpaid overtime [including working through meal breaks] that respondents carried out regularly per week, they were given five options to choose from. As a result, 16% [25/160] of respondents reported that they carried out no regular unpaid overtime; and 32% [51/160] carried out between 1 and 3 h unpaid work, 36% [57/160] 4 to 7 h, 10% [16/160] 7 to 10 h, and 7% [11/160] more than 10 h. This equates to approximately 661 h of unpaid overtime worked per week in total by respondents as a whole [assuming median values of 2, 5.5, 8.5, and 10 h extra for the four categories reporting unpaid overtime, respectively], or 4.13 h each which is equivalent to approximately 17.6 FTE unpaid overtime being worked per week in total.

3.5 Administrative support provided to respondents

Respondents were asked how much administrative [admin] support [help with typing letters or doing routine non-clinical administration] they received each week; 16% responded that they received no admin support at all. A further 45% responded that they only received admin support for clinic letters. Of the respondents who did

receive admin support to use as they wished, 4% received between 1 and 5 h of support, 9% between 6 and 12 h, 7% 13 to 20 h, and 19% more than 20 h per week.

3.6 Unfilled and frozen vacancies

To ascertain the level of unfilled and frozen posts, respondents were asked how many, if any, posts were unfilled in their specialty. Overall, 77% of respondents had no unfilled posts, 5% of respondents had less than one FTE unfilled, and 15% had one FTE unfilled. Finally, 3% of respondents had two FTEs unfilled. No respondents reported any frozen posts. This equates to approximately 24.5 FTE posts unfilled in total from this population.

3.7 Respondents' estimated caseload

Respondents were asked to estimate their individual caseload: 63% of respondents had caseloads over 700 patients and only 25% had caseloads of 500 or less [Figure 1]. Taken as a whole, this represents an approximate total caseload of 146 150 patients for all 148 respondents.

3.8 Respondents' work done

Respondents were asked if they carried out certain tasks at each level of the treatment pathway [pre-diagnosis, diagnosis, post-diagnosis, treatment, and end of treatment/follow up]. It can be seen that as a group, IBD NS are involved in all stages of the treatment pathway. The actual level of involvement in pre-diagnosis was not anticipated by the focus group, with only 55 respondents [41%] stating that they did not see patients at the pre-diagnosis stage. The highest period of activity was at the post-diagnosis stage. The responses are summarised in Figure 2. The six most common interventions at each treatment stage are shown in Figure 3, with meeting information needs,

symptom control, requesting imaging, and recommending medication being the most common interventions.

3.9 Respondent's sessional work

The respondents' work done by session is summarised in Table 2. Provision of an advice line was the most common single use of working time, with 85% of respondents spending at least three sessions

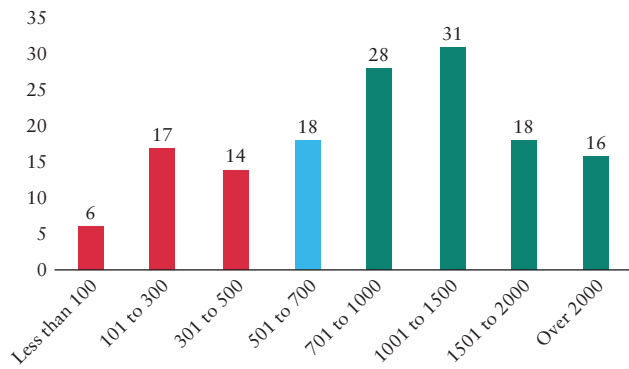


Figure 1. Respondents' annual caseload [148 responses]. The bar in blue [501 to 700 caseload] indicates where the recommended caseload of 666 (1.5 full-time equivalents [FTE] per 250 000) lies. The bars in green show where the caseload exceeds the standard.

a week on the advice line and a total of 560 [31% of the total reported sessions] sessions being spent by all respondents. Nurse-led outpatient clinics accounted for a further 290 sessions, more than twice the number of consultant-led outpatient clinics at 121 sessions. Endoscopy does not appear to be common, with only 36 sessions being reported.

3.10 Respondents' work left undone

Across all stages of treatment, psychological interventions [emotional support, referral to counselling and/or psychiatric services] feature highly in respondents' work undone and are the most common work undone at each stage after pre-diagnosis. Prescribing medication is another area where respondents felt much was left undone, perhaps because the nurses who gave this response did not have a prescribing qualification or were not able to prescribe independently. Work left undone is summarised in Figure 4.

4. Discussion

Specialist disease-specific nurses are known to enhance the quality of care and patient experience^{21,22} and can be productive not only in terms of quality but also in terms of efficiency, such as the avoidance of unnecessary admission to an acute inpatient unit.^{14,23} The value of an IBD NS was investigated by Leach *et al.* [2014] who examined 4920 recorded episodes of care in Australia, involving 566 patients.

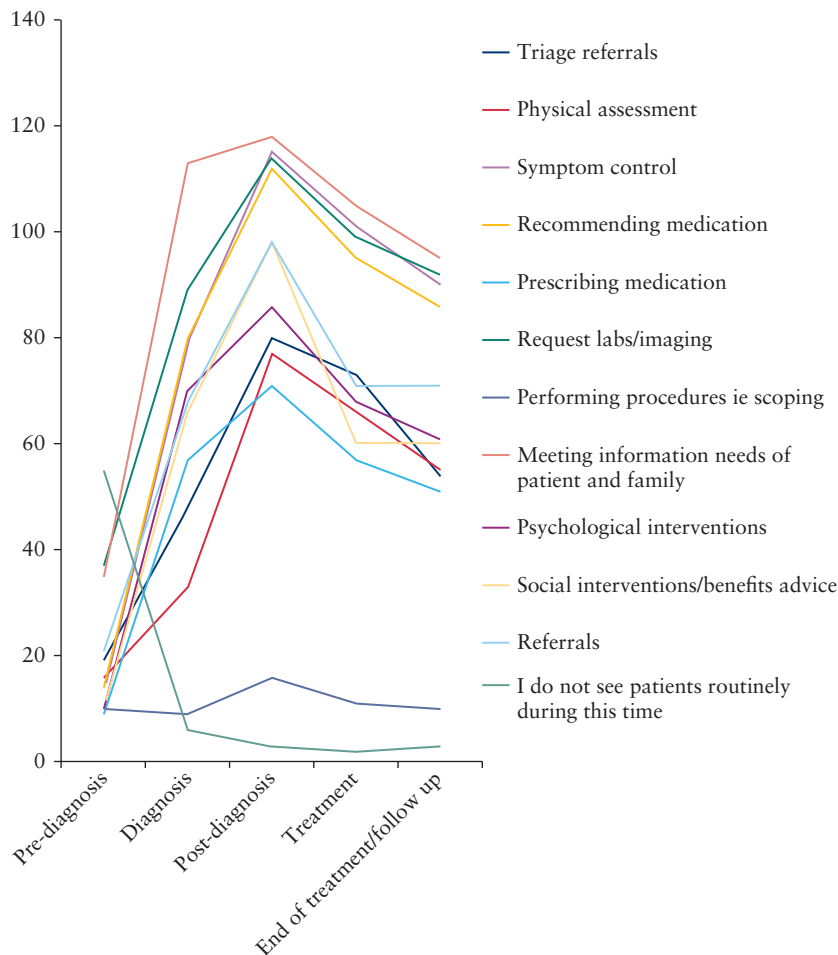


Figure 2. Respondents' work done [134 responses, respondents could choose multiple options].

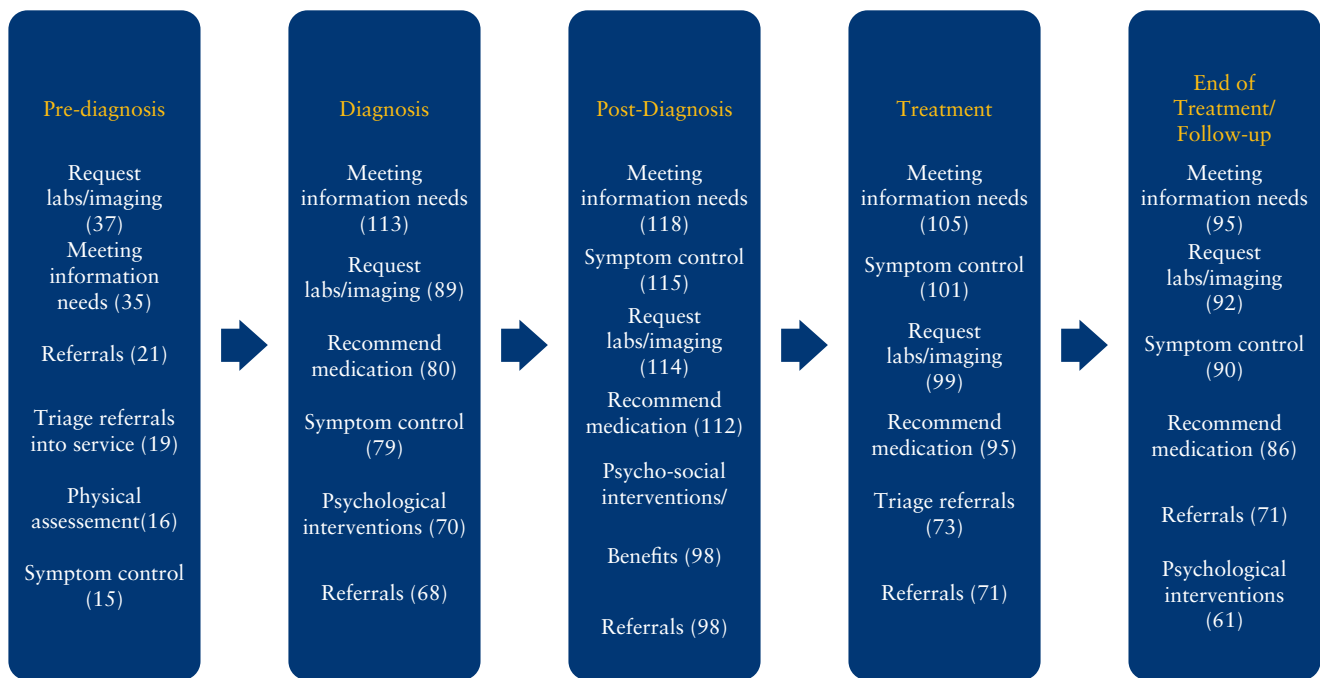


Figure 3. The six most common interventions at each treatment stage.

Table 2. Number of sessions spent on each work group per week

Work	Sessions
Advice line	560
Nurse-led outpatient clinic	290
Inpatient working	246
Telephone clinics	193
Infusions	142
Consultant-led outpatient clinic	121
Joint nurse/consultant clinic	78
Virtual clinic	78
Endoscopy list	36

IBD nurse intervention led to avoidance of 27 hospital admissions [representing a saving of 171 occupied bed-days], 32 emergency department presentations, and 163 outpatient reviews. After deducting salary and on-costs related to the IBD nurse, there was a net direct saving to the hospital of AUD \$136 535.²⁴ Another study looked at the financial impact of a nurse-led telemedicine service for IBD in a UK hospital, and estimated that over a 5-month period, the net saving on the avoidance of general practitioner consultations, consultant appointments, and either accident and emergency or hospital admissions, was £42, 890.²⁵ The value of such telemedicine services or helplines has been demonstrated by a number of studies. For example, a survey of 1143 people with IBD [46% response rate] in Canada found that 77% of respondents were likely or very likely if acutely symptomatic to use a phone contact service with an IBD NS.²⁶ As with any supply model, there is likely to be a point of saturation whereby the quality of the service is at least partly driven by the distributed workload, which can result in work being left undone.²⁷

Given that the total population of IBD patients in the UK is estimated at 250 000 to 300 000, the estimated 146 150 case load covered by the respondents in this study equates to between 49% and 58% of the total IBD patient population. This is supported by the

estimate that the total IBD NS population in the UK is around 300, so 148 responses to the caseload question would represent around 50% of the IBD NS population. The distribution of respondents in the UK also reflects the distribution of IBD NS posts reported in the IBD nursing audit.³

The IBD standards⁷ recommended that 1.5 FTE NS with a special interest and competency within IBD should be provided per 250 000 of population for a 5-day service. Assuming that 1 in 250 of the population has IBD, this would give a caseload of 666 per FTE IBD NS.

Crohn's and Colitis UK⁵ states that the current number of patients with IBD in the UK is 300 000. To achieve a caseload of 666 patients per full-time IBD NS would therefore require 450 full-time IBD NS, based on current demand. There appears to be a considerable shortfall in this number in the UK. In this group, of the 148 nurses who responded to this workload analysis, over half [63%] have much higher caseloads than the current recommended standard. Caseloads as high as 2000 patients plus were reported.

There are number of potential reasons for these high caseloads. One potential issue is unfilled IBD NS posts. In this study, the number of unfilled posts reported by respondents is estimated to be equivalent to 24.5 FTE. Another factor which is apparent from the study is the amount of unpaid overtime currently being carried out by IBD NS. In 2012, the RCN estimated that IBD NS carried out an average of 2.75 h unpaid overtime per week,⁶ suggesting that on the basis of an estimated average of 4.13 h in this study, the amount of unpaid overtime carried out by IBD NS is increasing. Only 16% of respondents regularly carried out no unpaid overtime. The amount of unpaid overtime carried out by the remaining respondents equalled an estimated 17.6 FTE. The 2012 RCN IBD Nursing Audit⁶ found that 79% [150/202] sites surveyed failed to meet the standard of 1.5 IBD NS per 250 000 population, and the data presented in this study would appear to suggest there has not been significant improvement since 2012.

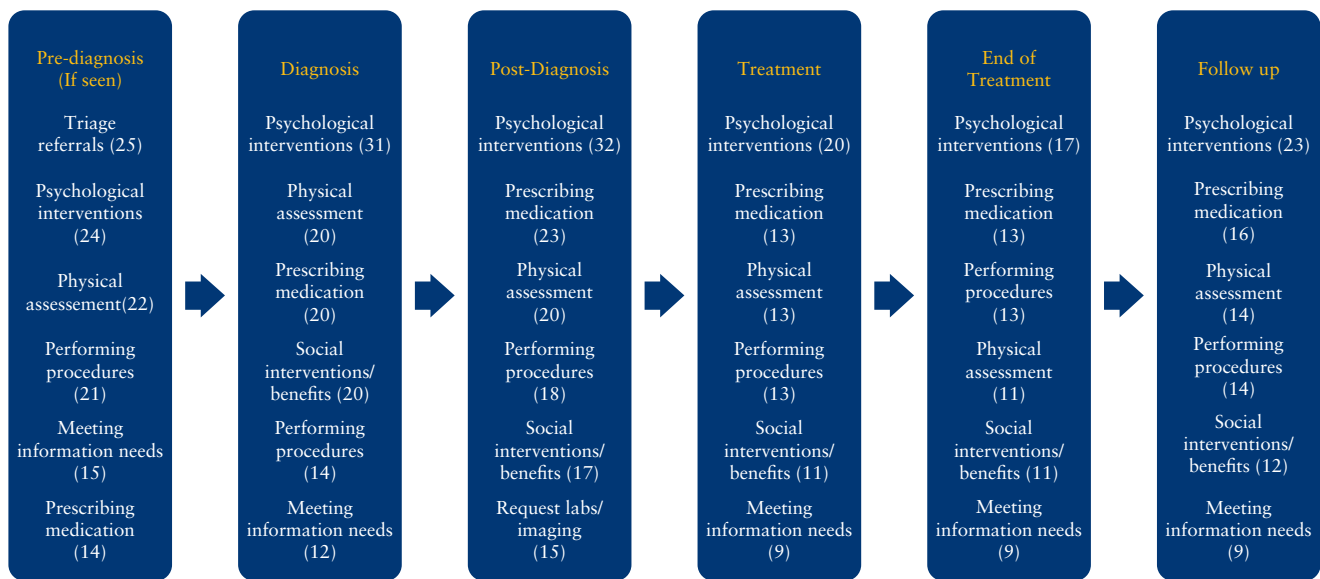


Figure 4. The six most common areas of interventions left undone at each stage of the treatment pathway.

It is clear from the workload analysis that there is much variability and different levels of service provision. Of the 1800 available sessions in the group, 1744 [97%] were taken up with programmed clinical activity. The majority of this time was a telephone advice line [560, 31%], and only 290 sessions [16%] were taken up with nurse-led clinics. The IBD standards report⁷ found that only 24% of patients had access to a psychologist with an IBD interest, which may explain why this work is often left undone.

It is also apparent that because of the variability of service provision, local circumstances should be taken into account, such as the availability of administrative help—which remains a burden for some IBD NS. In other specialties the provision of administration and support workers has increased productivity; for example, administrative workers allowed multiple sclerosis specialist nurses to proactively manage their caseload, resulting in reduced emergency admission.²⁸ Another local factor which can influence caseload is the complexity of patients.

5. Conclusion

The current standard 1.5 FTE IBD NS per 250 000 population, if filled, is likely to mitigate the rates of unpaid overtime and annual leave. However, there is a clear direction of travel for increasing complexity of care, activity at pre-diagnosis, support to community services, and a 'rookie' workforce [including a rookie factor uplift of 20%]. This is because this workforce of IBD NS, compared with other groups of specialist nurses,^{8,11} have a much higher proportion who have been in specialist practice for less time (61 [36%] had been working as specialist nurses for less than 3 years). Only 51 [32%] had been working the role for 10 years or more. A study looking at research priorities for IBD nursing in 13 European countries found that 23.8% of respondents had worked in IBD for 3 years or less, with 28.4% having worked for over 10 years.¹¹ In prostate cancer nurse specialists [CNS], for example, 55% of NS had been in post for 10 years or more.⁸ To mitigate this, it would be prudent to increase the standard to 2.5 FTE per 250 000 of the population. This would give a static caseload of 500 per FTE.

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Conflict of Interest

IM is head of Service Development for IBD nurses at Crohn's and Colitis UK. No other conflicts of interest are reported.

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Author Contributions

AL and GP contributed to study design, data collection, data analysis, and manuscript preparation. IM contributed to study design, data collection and manuscript preparation. The authors confirm that the manuscript, including related data, figures, and tables, has not been previously published nor is the manuscript under consideration elsewhere.

Supplementary Data

Supplementary data are available at *ECCO-JCC* online.

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