

**Modelling Caseload Standards for IBD
Specialist Nurses in the UK**

April 2017

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Executive Summary

- Based on current average workload and to achieve optimum pro-active management of care, this study recommends a caseload of 2.5 Full Time Equivalent (FTE) IBD specialist nurse per 250,000 population. This gives a static caseload of 500 per FTE.
- A supporter survey from Crohns and Colitis UK in 2016 showed 29-38% reported having no contact with an IBD specialist nurse as part of their service.
- The current recommended caseload for IBD specialist nurses is 666 patients (or 1.5 FTE per 250,000 population) per FTE nurse which although adequate for reactive management does not allow for proactive management, advancing practice, cover arrangements and is not optimal for care.
- CCUK 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 CNS would therefore require 450 full-time IBD CNS based on current demand. There appears to be a considerable shortfall on this number in the UK. In this group, of the 148 nurses who responded to the question about caseloads, over half (63%) have much higher caseloads than the current recommended standard.
- The nurses who supplied data (n=164 RR 55% of total estimated population) covered approximately 146,000 patients in total.
- Compared to other specialities IBD specialist nurses have been working in specialist practice for a shorter period of time (for example 52% had less than 7 years' experience compared to 25% of prostate cancer specialist nurses).
- IBD specialist nurses have to contribute a considerable amount of unpaid overtime (4.13 hours per week each on average, equal to 17.6 FTE per week in total in this group) to cope with the needs of their patient population. This is exacerbated where administrative support is limited. Unfilled posts accounted for another 24.5 FTE which, taken together with the unpaid overtime, equals a 41.1 FTE shortfall in posts currently.
- While almost half of the of IBD specialist nurses have (43% of respondents) a prescribing qualification only 14% have a Masters in advanced practice which is the current standard for credentialing with the Royal College of Nursing for advanced level practice. To achieve a greater number of advanced practice nurses, this is an issue which needs to be addressed in light of the reduction in funding for continuing professional development nationally.
- IBD specialist nurses generally have a positive experience of Multidisciplinary Team working (MDT) and feel able to fully contribute and advocate for patients within the MDT
- The role of the IBD specialist nurse is a complex case managing role involving interacting with many other specialities to deliver care for the patient population over their entire treatment pathway from diagnosis to continuing care. 79 respondents (59%) were carrying out work at the pre-diagnosis stage. Only 55 respondents (41%) stated that they did not carry out work at the pre-diagnosis stage.

Introduction

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. IBD is a lifelong condition as there is currently no cure. Half of all newly diagnosed patients will be in their teens and twenties¹.

It is widely accepted that access to effective IBD nurse specialist services improves experience and clinical outcomes for supporters². Patients often describe their IBD nurse specialist service as a lifeline. At Crohn's and Colitis UK the value and impact of the IBD nurse specialist role is at the heart of the charity's strategy to improve quality of care.

The National Standards for IBD Care³ first defined the numbers of nurse specialists required as 1.5 FTE per 250,000 population

The current national standards have been very influential in increasing nursing numbers, however, they are not evidence based, and don't reflect the complexity of nurse specialist work.

As part of the 'More IBD nurses – Better Care Campaign' the aim was to publish a new, robust, validated national standard and recommended caseload.

Method and Data Collection

Consensus workshop of expert opinion

In order to use the existing a priori dataset on the work of specialist nursing in the UK (n~18,000) and the on-line data collection tool it was necessary to check assumptions regarding the workload and activity of this group.

A consensus workshop of 15 IBD nurse specialists from across the UK was convened to check and challenge assumptions.

Data collection methods

A 24-item questionnaire, exploring demographic data, caseload and workload and experience of MDT working was developed for this population by consensus using clinical, patient and academic experts based on a previously used questionnaire⁴. 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 project⁵. This was transferred to an online survey tool (administered using a Survey Monkey secure account). The link was distributed through the RCN IBD Nursing Network, mailing lists during February 2017. 164 participants could only submit a single response from each computer. Analysis of the data took place in March 2017.

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. Pattern recognition was used to identify factors such as workload. Free text comments were analysed using thematic content analysis⁶. 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'.

Caseload Standards Summary

There are currently 300 specialist IBD nurse specialists in 170 centres working in the UK (Source: CCUK).

The IBD Standards (2013 update)³ recommend that 1.5 full time equivalent (FTE) nurse specialists in IBD are provided per defined population of 250,000. Assuming that the incidence of IBD in the population is 1 in 250 this equates to a caseload of 1,000 patients for the recommended 1.5 FTE CNS or 666 patients per full time IBD CNS.

CCUK 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 CNS would therefore **require 450 full-time IBD CNS based on current demand**. There appears to be a considerable shortfall on 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.

The current standard 1.5/250,000 population if filled is likely to mitigate for 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 compared to other groups of specialist nurses⁴ IBD specialist nurses 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. To mitigate this, it would be prudent to **increase the standard to 2 FTE per 250,000 of the population**. This would give a static caseload of 500 per FTE.

Other factors

It's clear from the workload analysis that there is much variability and different levels of service provision. Of the 1,800 available sessions in the group 1,744 (97%) were taken up with programmed clinical activity. The majority of this time was advice line (560, 31%) and only 290 sessions (16%) were taken up with nurse led clinics. Despite almost half (43%) having a prescribing qualification only 22 (14%) had a masters or advanced practice course. In other studies, advanced practice releases the time of other professionals and **if the aspiration is to become a fully advanced level practice specialism an uplift of 50% i.e. 2.5**

per 250,000 would add the extra capacity to develop the specialism into an end to end nursing service with nurses able to deliver complete episodes of care.

In other specialisms, particularly long term conditions, practicing at an advanced level⁷ is common with specialist nurses taking on the bulk of the management of care⁸. Many now provide complete episodes of care within a multidisciplinary framework^{9,10} and this allows improved continuity of care, more timely care and also frees the time of other professionals such as consultants.

It is also worth noting that because of the variability local circumstances should be taken into account such as the availability of administrative help which remains a burden for some in the group, the complexity of patients (the basis of the figures above was a median level of complexity as defined by this group- extremes of work would require a local solution).

Detailed Analysis and Results

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 IBD CNS in the UK is around 300 by headcount (FTE is unknown) so this equates to a 55% response rate.

Country of Practice

Respondents were asked to state their country of practice. Of those who responded 76% (124/164) were based in England, 2% (3/164) in Northern Ireland, 12% (20/164) in Scotland and 8% in Wales (13/164). (4/164) 2% of the respondents were from 'Other' countries of practice (Table 1). This reflects the distribution of posts reported in the IBD audit (2013)³.

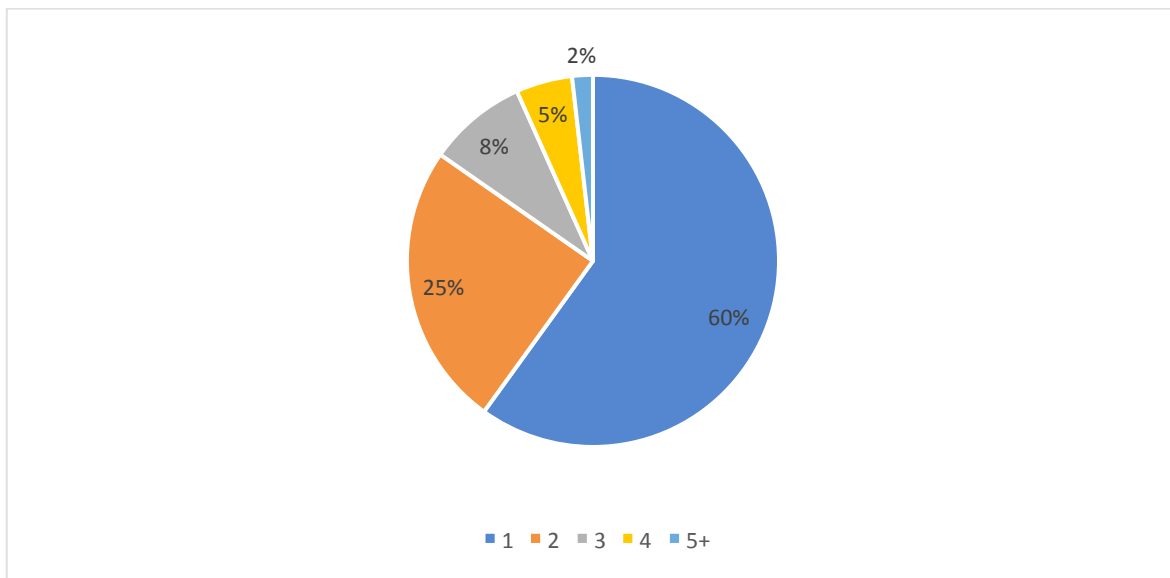
Table 1: The Country of Practice of Respondents.

Country of Practice	Responses
England	124
Northern Ireland	3
Scotland	20
Wales	13
Other	4
Total	164

Number of Hospital Sites Covered

To determine how many sites respondents covered they were asked to choose from 1, 2, 3, 4 or 5 plus sites. Hospital sites were taken to include all types of hospital such as acute, community etc. The majority of respondents covered a single hospital site (60%). Two sites were covered by 25% of respondents, three by 8%, four by 5% and five or more by 2% of respondents (Figure 1). No respondents worked only in the community setting.

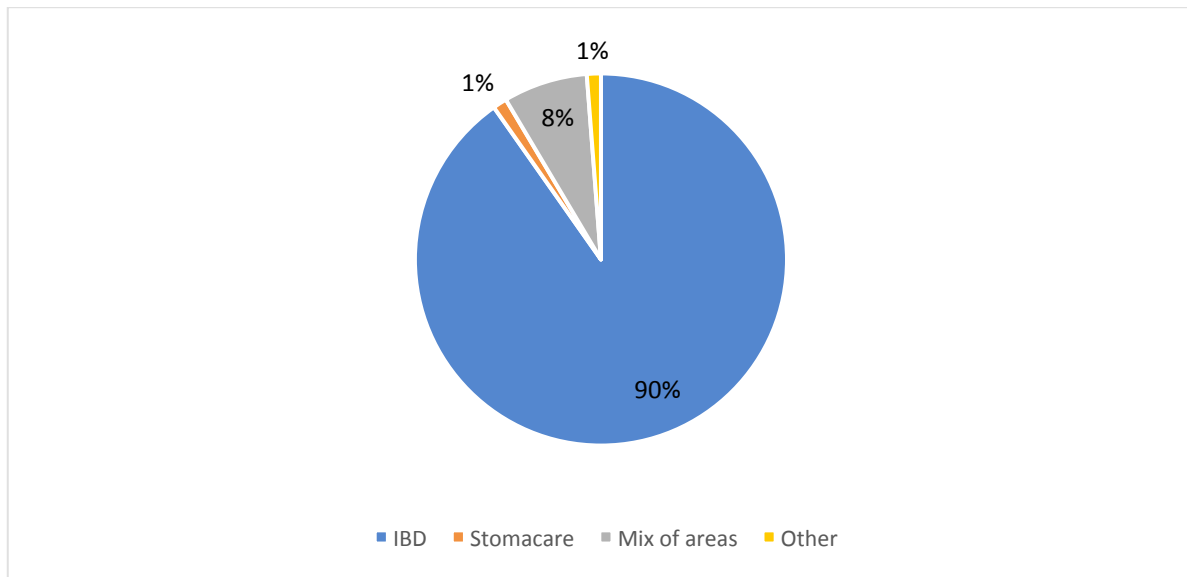
Figure 1: The number of hospital sites covered by each nurse (162 responses).



Area of Practice of Respondents

IBD was the most common area of practice with 90% of respondents working in this area. 8% of respondents worked in mixed practice (IBD, Surgery, Research/Clinical Trials, Infusion, Stoma Care, Nutrition, Hepatology and Nurse Endoscopy), 1% in Stoma Care and 1% in 'Other' areas (Figure 2).

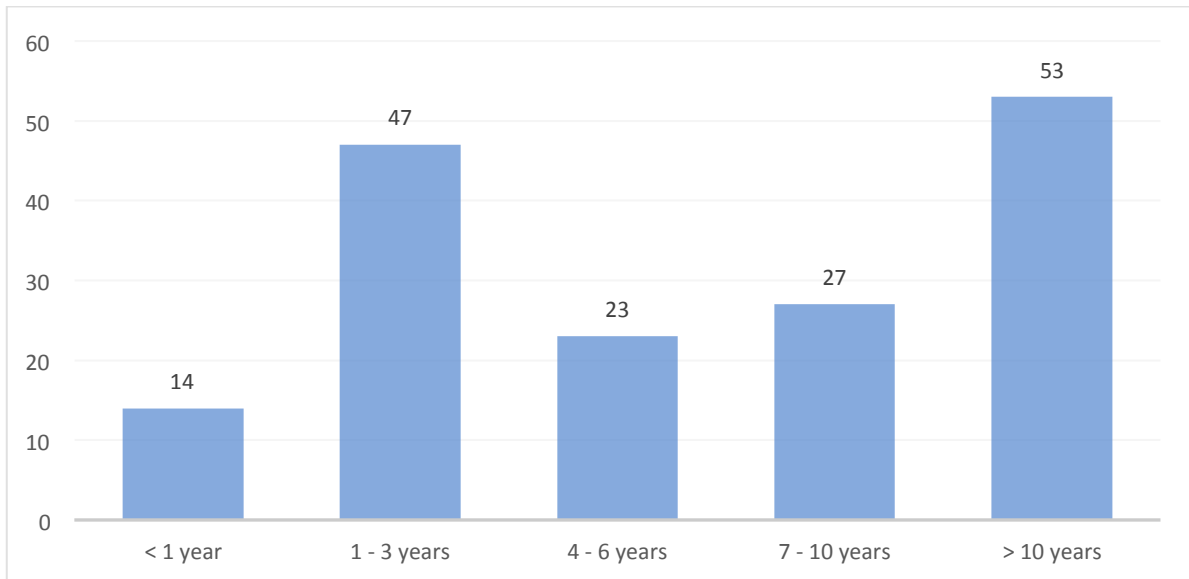
Figure 2: Area of Practice of respondents (164 responses).



Length of Time Working with IBD Patients

In order to measure the experience levels of respondents they were asked how long they had been working with IBD patients. 9% of respondents had less than a years' experience working with IBD patients. One to three years' experience was reported by 29% of respondents, 4 to 6 years by 14% and 7 to 10 years' experience by 16%. Over 10 years' experience was reported by 32% of respondents. This is summarised in Figure 3.

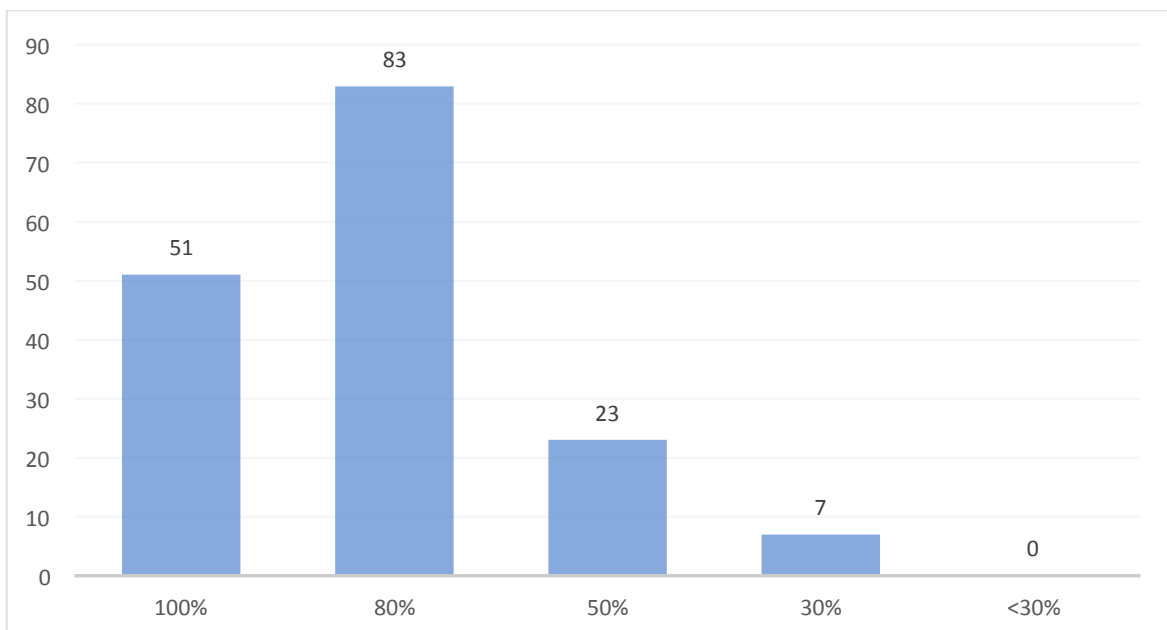
Figure 3: Length of Time Working with IBD Patients in years (164 responses).



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 time they spent providing care for IBD patients. No respondents spent less than 30% of their time working with IBD patients.

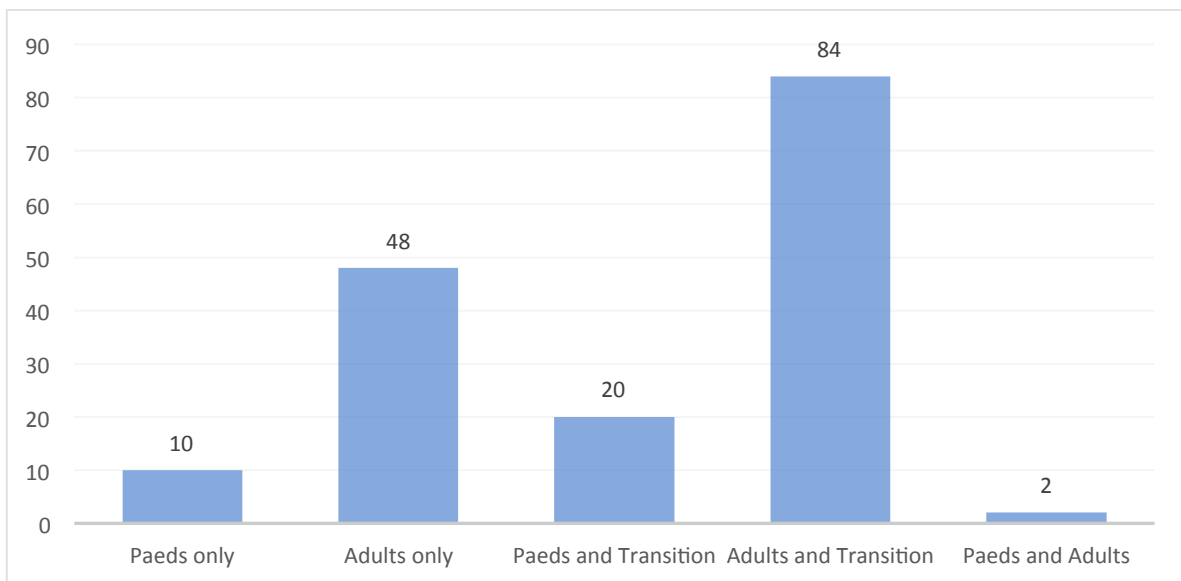
Figure 4: Estimated Percentage of Time Spent Working with IBD Patients (164 responses).



Area of IBD Practice

In order to determine which area of practice respondents worked in they were asked to select from five options: paediatrics only, adults only, paediatrics and transition, adults and transition or paediatrics and adults. The most common area was adults and transition (51% of respondents) followed by adults only (29%), paediatrics and transition (12%), paediatrics only (6%) and finally paediatrics and adults (1%). This is summarised in Figure 5.

Figure 5: Respondents Area of IBD Practice (164 responses).

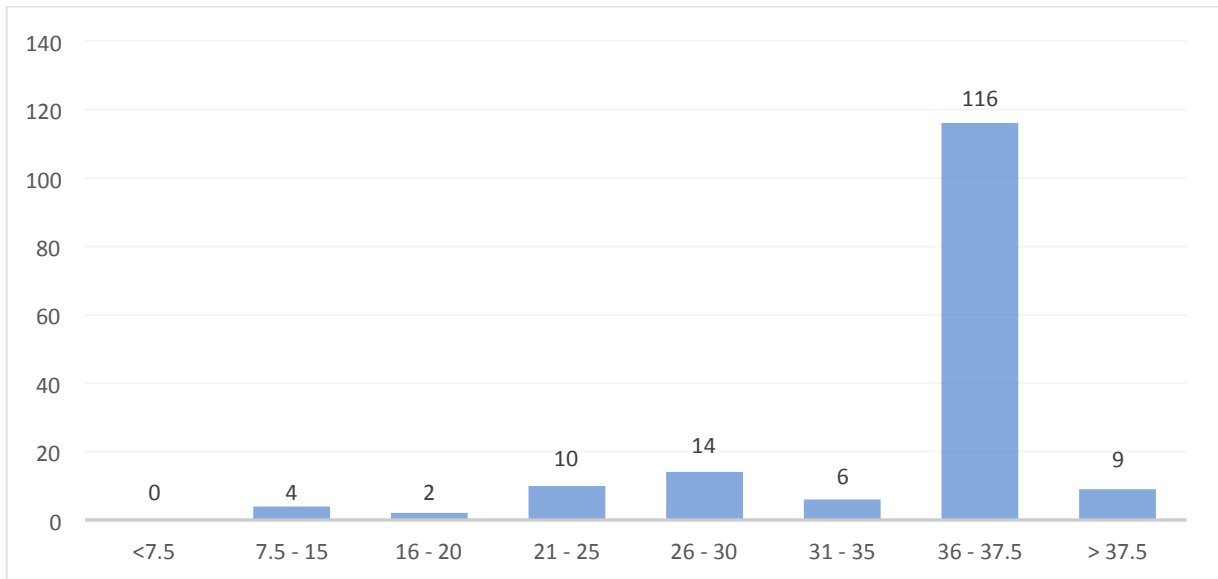


Contracted Hours of Work

Respondents were asked to state their contracted hours of work. 72% of respondents were contracted to work 36 to 37.5 hours per week. 9% worked 26 to 30 hours, 6% worked 21 to 25 hours, 6% more than 37.5 hours, 4% 31 to 35 hours, 2% 7.5 to 15 hours and 1% 16 to 20 hours (Figure 6).

In total this represents 149 FTE for the 161 respondents.

Figure 6: Contracted Hours Worked per Week (161 responses).



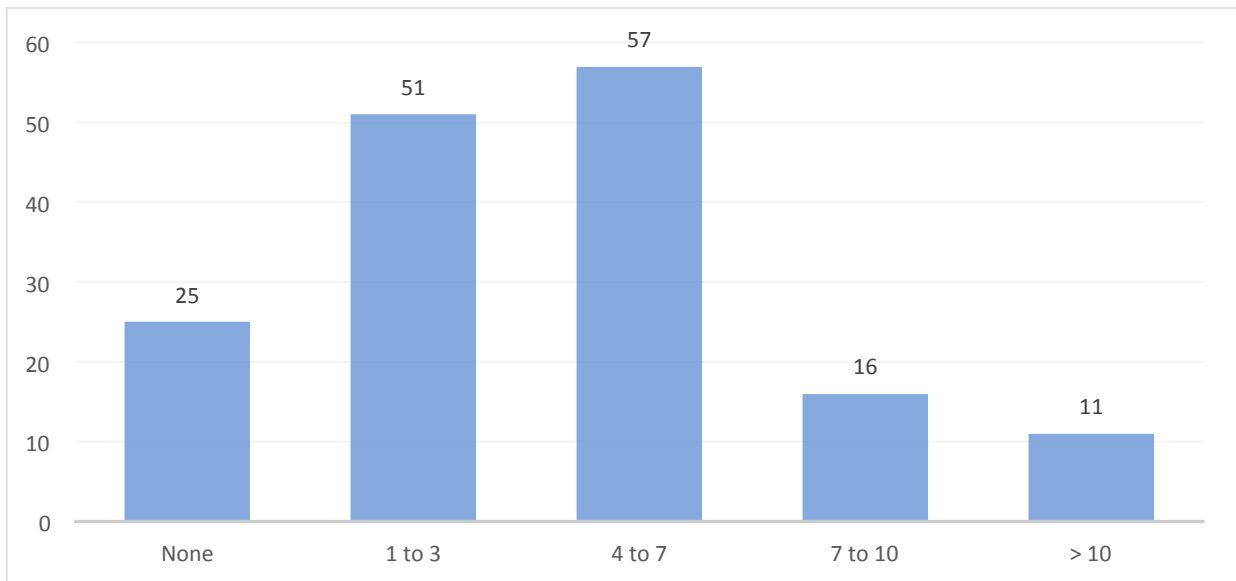
Unpaid Overtime Worked per Week

To ascertain how much unpaid overtime (including working through meal breaks) respondents carried out regularly per week they were given five options to choose from. 16% of respondents reported that they carried out no regular unpaid overtime. 32% carried out between 1 and 3 hours' unpaid work, 36% 4 to 7 hours, 10% 7 to 10 hours and 7% more than 10 hours. The amount of unpaid overtime regularly worked per week is shown in Figure 7.

This equates to approximately 661 hours of unpaid overtime worked per week in total for all respondents together (assuming median values of 2, 5.5, 8.5 and 10 hours extra for the four categories reporting unpaid overtime).

In total this represents 17.6 FTE unpaid overtime being worked per week by the 160 respondents.

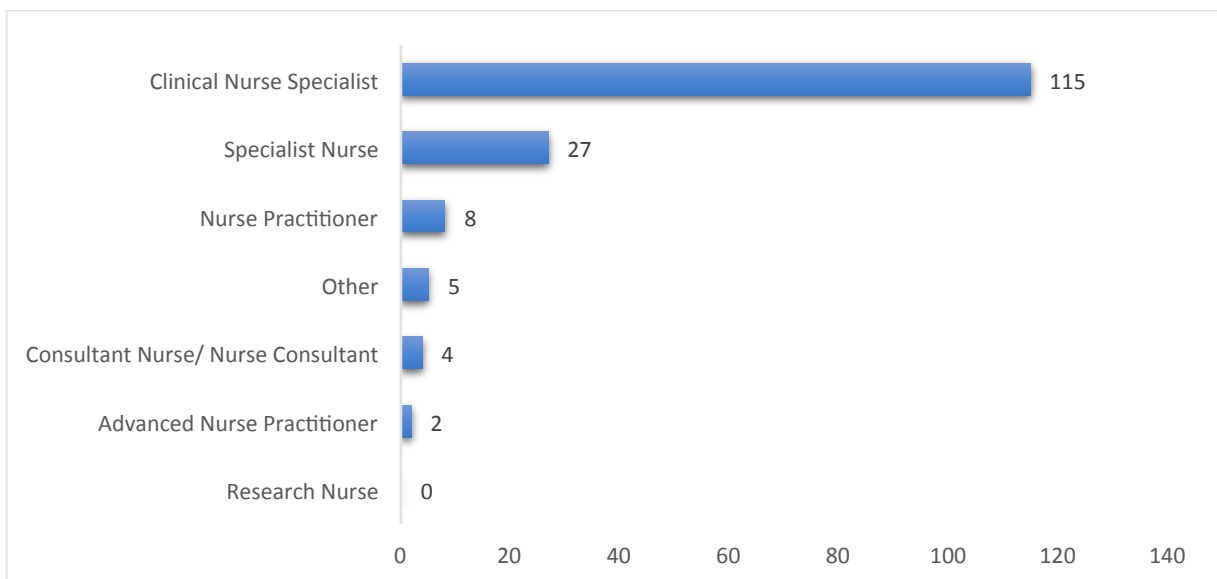
Figure 7: Unpaid Overtime Hours Worked Regularly per Week (160 responses).



Respondent's Job Title

By far the most common job title for respondents was 'Clinical Nurse Specialist' with 71% of respondent's having this title. Of the remainder 'Specialist Nurse' was reported by 18%, 'Nurse Practitioner' by 5%, 'Nurse Consultant/Consultant Nurse' by 2% and 'Advanced Nurse Practitioner' by 1%. 3% of respondents opted for 'Other' (Figure 8).

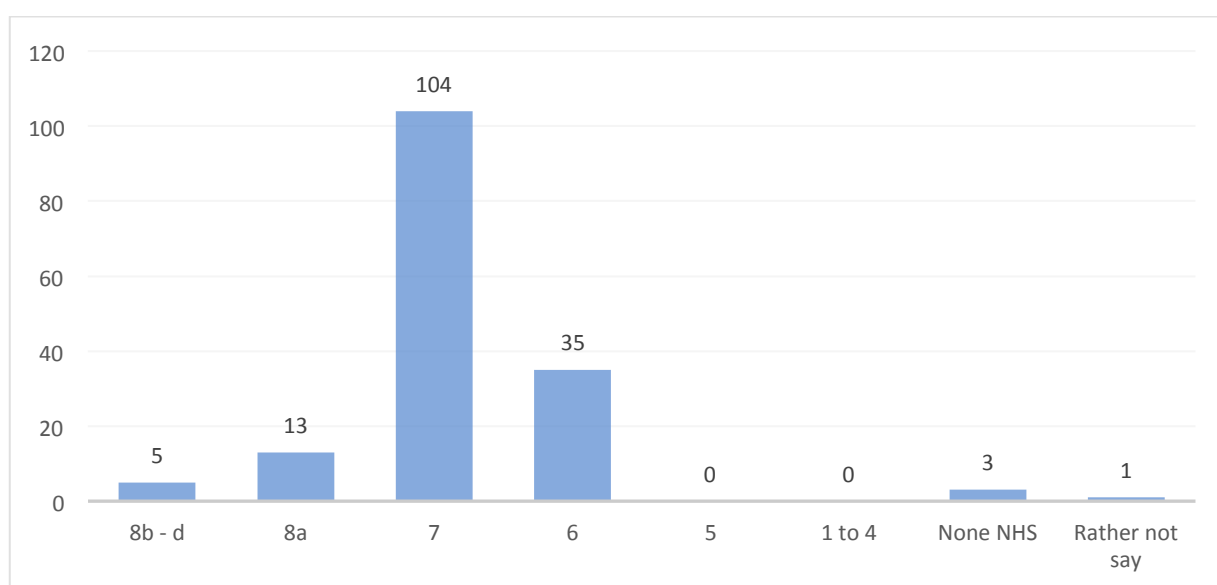
Figure 8: Job Titles Reported by Respondents (161 responses).



Respondents Working Grade

To determine which grade respondents worked at they were asked to state which NHS Band their role was graded at. The most common Band was Band 7 with 65% of respondents opting for this Band. Band 6 was reported by 22%, Band 8a by 8% and Band 8b-d by 3%. No respondents reported Band 5 or Bands 1-4 while 2% reported that they were graded on non-NHS schemes and 1% of respondents preferred not to say which Band they were (Figure 9).

Figure 9: Respondents Working Grade (161 responses).



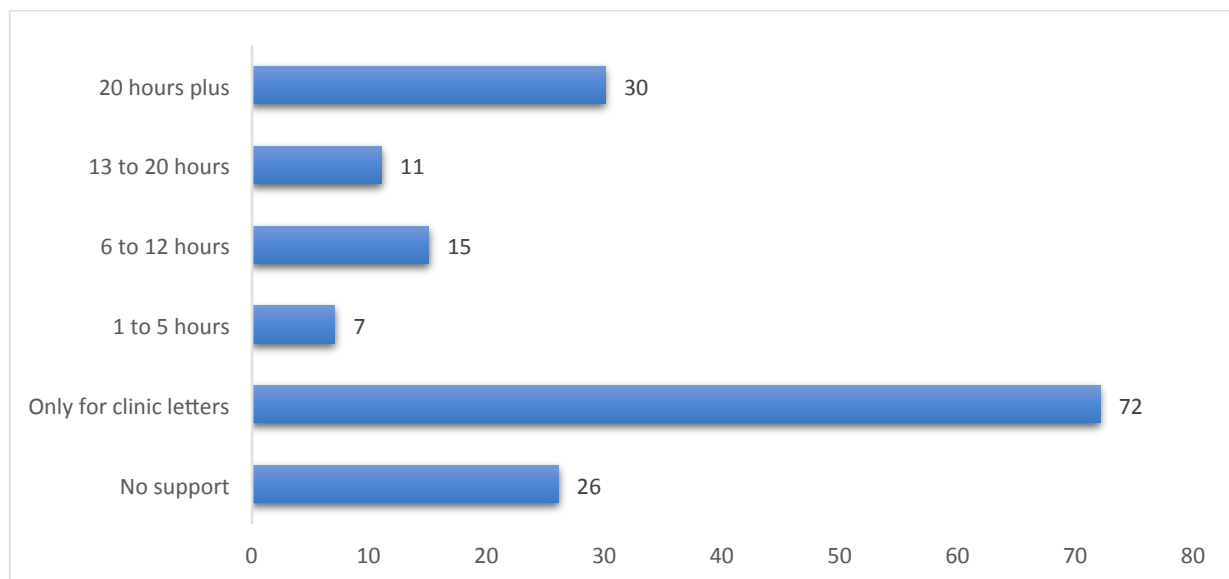
Administrative Support Provided to Respondents.

Respondents were asked how much administrative 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.

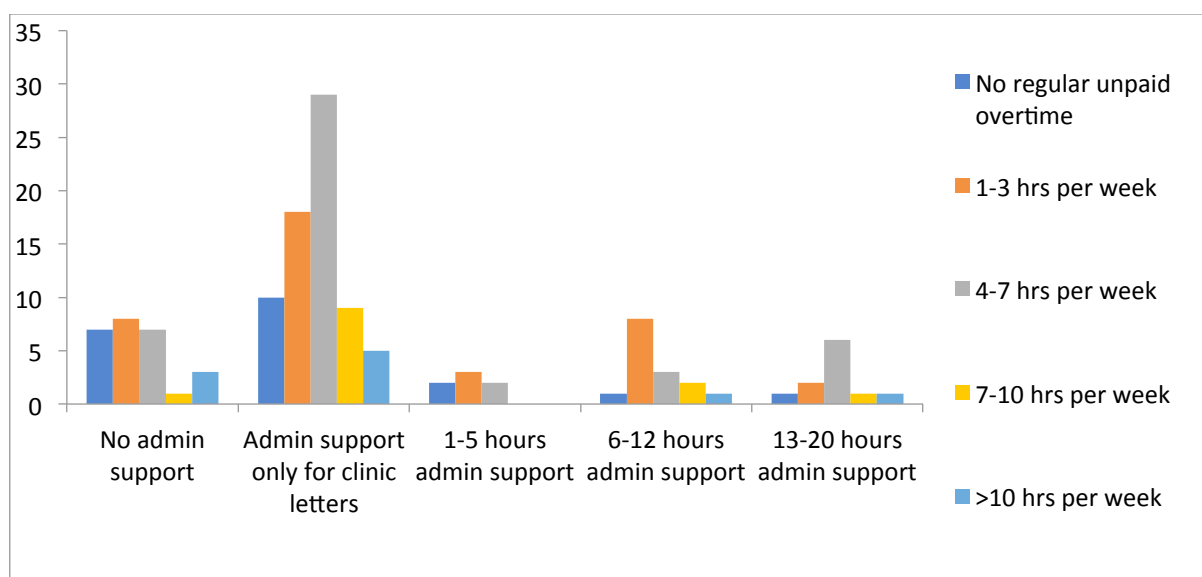
Of the respondents who did receive admin support to use as they wished 4% received between 1 and 5 hours' support, 9% between 6 and 12 hours, 7% 13 to 20 hours and 19% more than 20 hours per week (Figure 10a).

Figure 10a: Respondents Admin Support per Week in Hours (161 responses)



The relationship between admin support and overtime is examined in Figure 10b.

Figure 10b: The relationship between overtime and admin support levels.



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 speciality. 77% of respondents had no unfilled posts. 5% of respondents had less than one FTE unfilled while 15% had one FTE unfilled. Finally, 3% of respondents had two FTE unfilled. No respondents reported any frozen posts.

This equates to approximately 24.5 FTE posts unfilled in total from this population. Added to the 17.6 FTE per week in unpaid OTE this gives a total deficit of 42.1 FTE in this group.

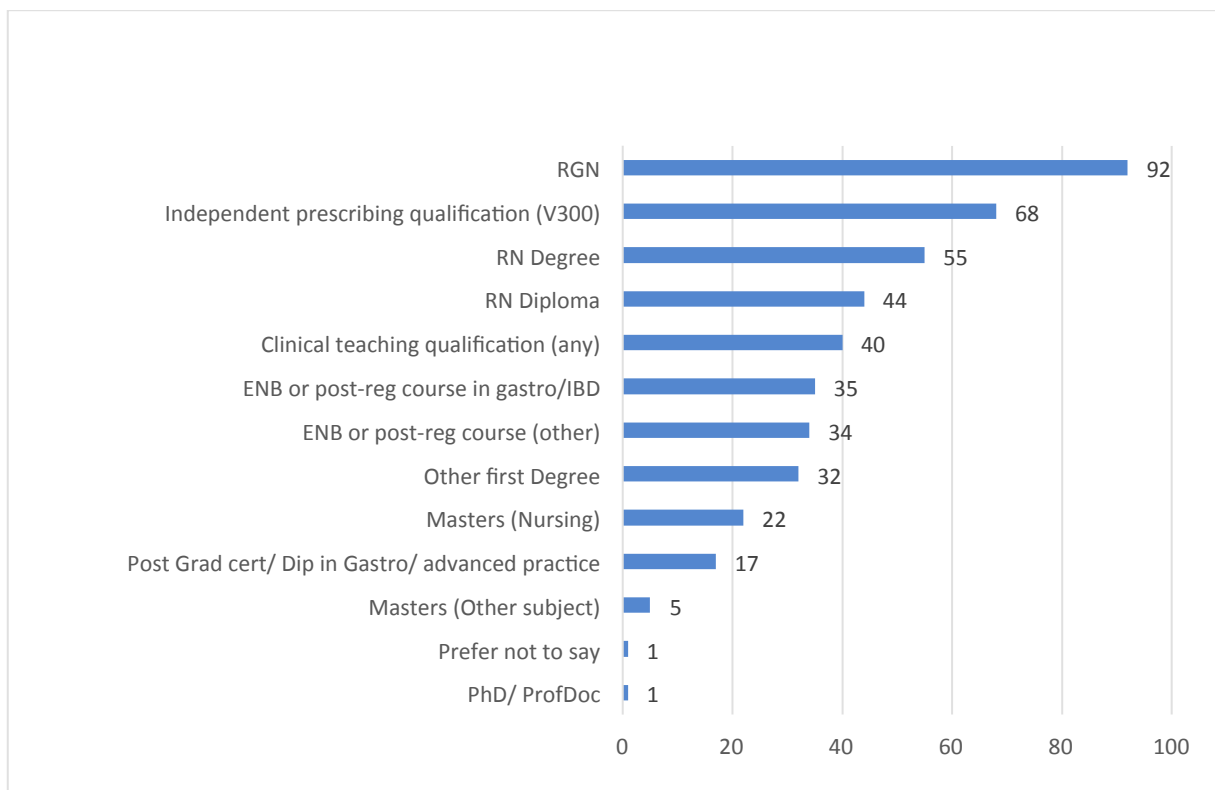
Respondents Qualifications

The most common qualifications are RGN (58% of respondents), an independent prescribing qualification (43%), an RN degree (35%) and an RN Diploma (28%).

The RCN IBD Nursing Audit (2012)² stated that IBD nurses had a ‘disappointing’ level of formal qualifications which appears to still be the case with regard to Masters level qualifications. The same audit found that IBD CNS were central to complex drug management so the proportion of CNS with an independent prescribing qualification is relatively high. The respondents’ qualifications are summarised in Figure 11.

43% of the respondents held an independent prescribing qualification

Figure 11: Respondents Qualifications (158 responses, respondents could choose more than one choice).



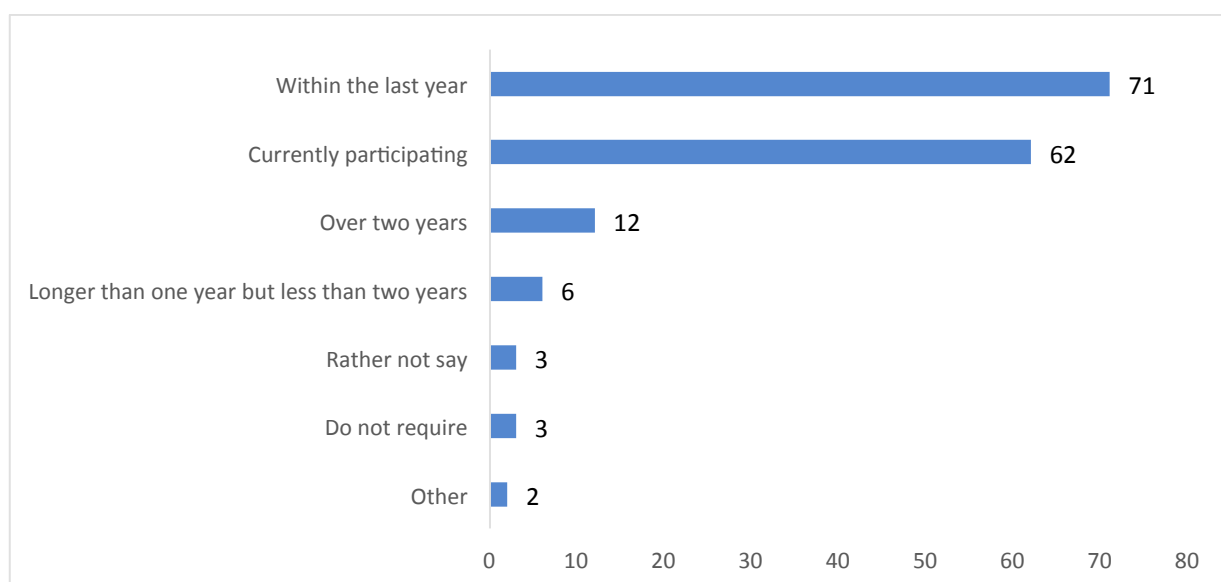
Respondents Access to Education

Respondents were asked about their access to post-registration specialist education or continuing professional development (not including mandatory training) with the responses being shown in Figure 12. Given that the IBD Standards report (2013)³ stated that all members of the IBD team should participate in local and national education participation by the respondents was relatively high:

The majority of respondents (82%) were currently participating in CPD/education or had done so within the last 12 months.

In addition, 22% of respondents reported finding it hard to obtain funding for education and to take study leave.

Figure 12: Respondents Access to Education (159 responses).

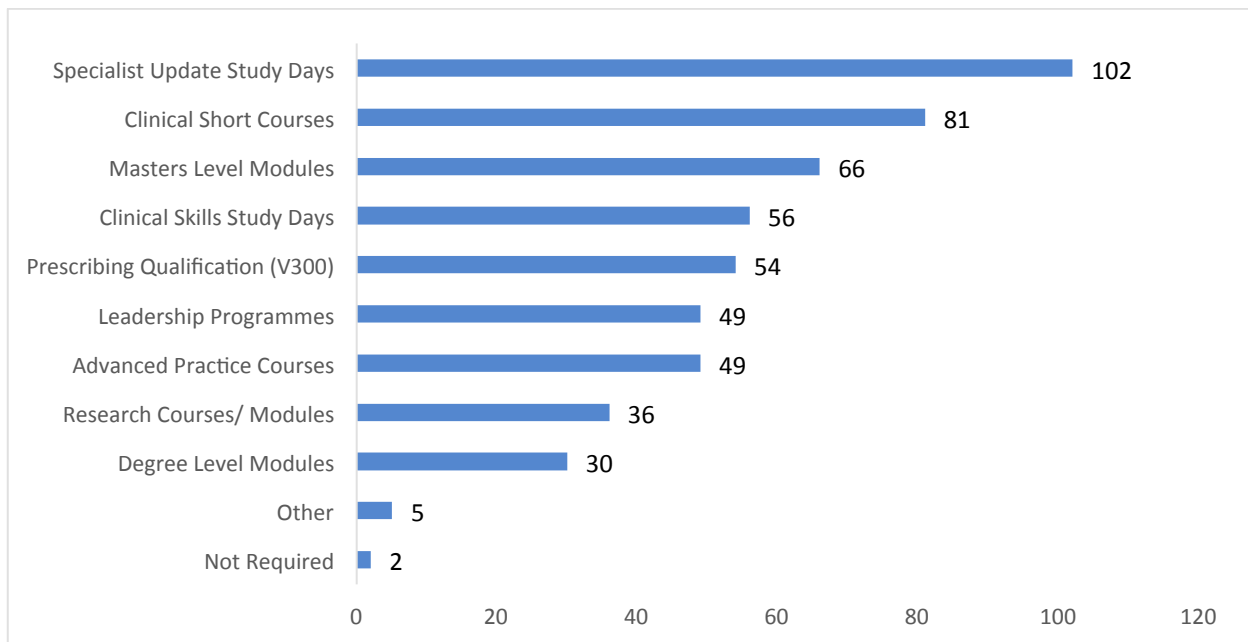


Respondents Interest in Access to Educational Programmes

Respondents were asked which educational programmes they would like to access if funding and time was made available to them. There was interest in all areas of education with specialist study days (67%), clinical short courses (53%) and masters level modules (43%) being the most popular responses.

Given that 43% of respondents already had a prescribing qualification and presumably would not choose this option in their educational needs it is noticeable that 35% of the total respondents to this question would like to have access to a prescribing course suggesting that this is seen as a very significant qualification to have by the respondents in general.

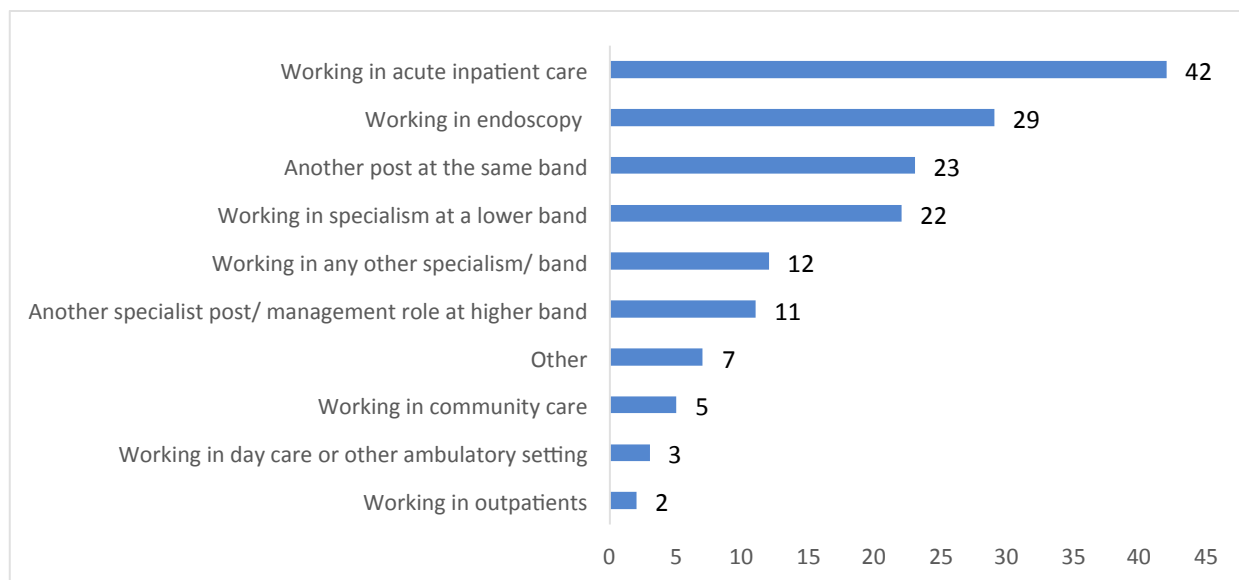
Figure 13: Respondents Educational Access if given funding and time (153 Responses, respondents could choose more than one option).



Respondents Last Role before Current Role

The pipeline for the role primarily comes from acute inpatient care. This is unusual as these roles often result from ambulatory care in other specialisms.

Figure 14: Respondents Last Role Held Prior to Current Role (156 Responses).



Respondents Estimated Caseload

Respondents were asked to estimate their individual caseload. 63% of respondents had caseloads over 700 patients while only 25% had caseloads of 500 or less (Figure 15). Taken as a whole this represents an approximate total caseload of 146,150 patients for all 148 respondents.

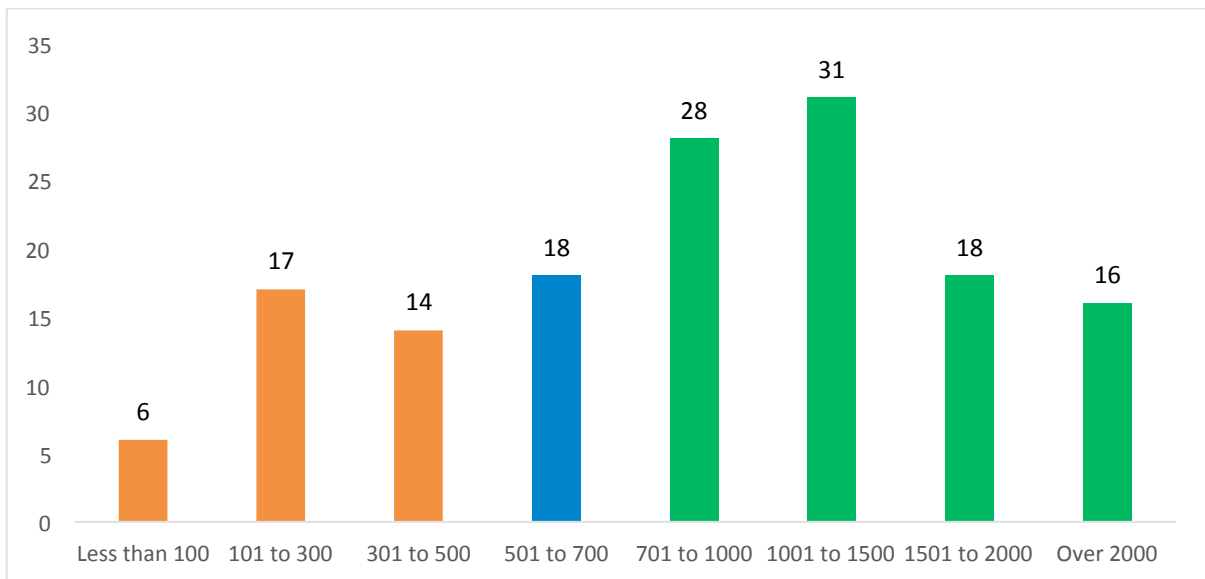
Given that the total population of IBD patients in the UK is estimated at 250,000 to 300,000 the estimated 146,150 caseload covered by the respondents equates to between 49% and 58% of the total IBD patient population (this fits well with the estimate that the total IBD CNS population in the UK is around 300 so 148 responses to the caseload question would represent around 50% of the CNS IBD population).

The 2012 RCN IBD Nursing Audit² found that 79% (150/202) sites surveyed failed to meet the standard of 1.5 IBD specialist nurses per 250,000 population.

The IBD Standards (2013 update)³ recommend that 1.5 FTE CNS with a special interest and competency within IBD should be provided per 250,000 of population for a five-day service. Based on the assumption that 1 in 250 of the population has IBD this would give a caseload of 666 per FTE.

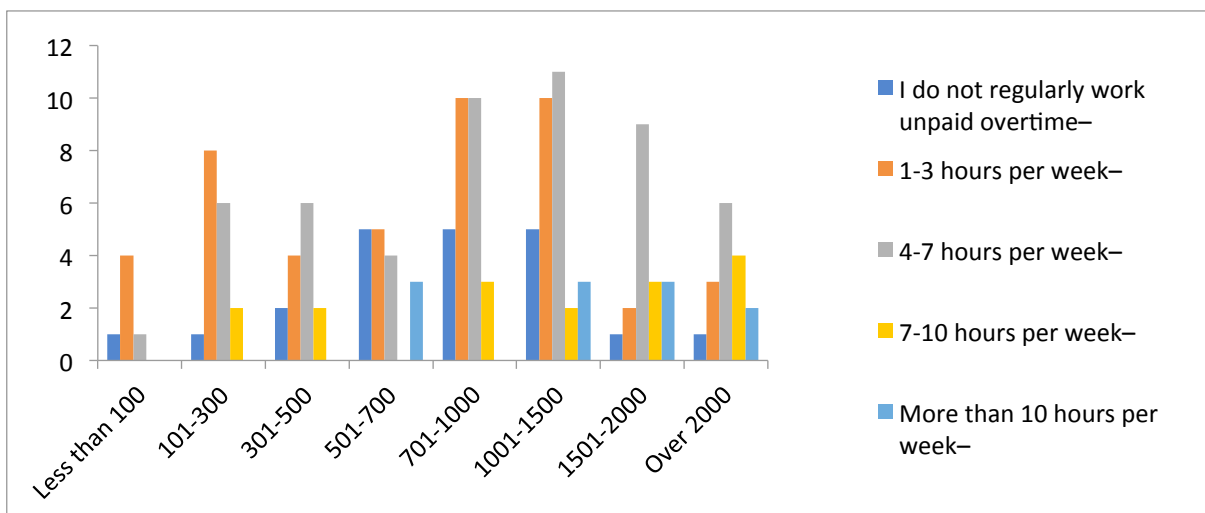
It can be seen from Fig 15a that of the 148 nurses who responded over half (63%) have much higher caseloads than the current recommended standard. This suggests that there has only been a limited improvement from the situation reported by the 2012 RCN IBD Nursing Audit².

Figure 15a: Respondent’s annual caseload (148 responses). The bar in blue (501 to 700 caseload) indicates where the recommended caseload of 666 (1.5 FTE per 250,000) lies. The bars in green show where the caseload exceeds the standard.



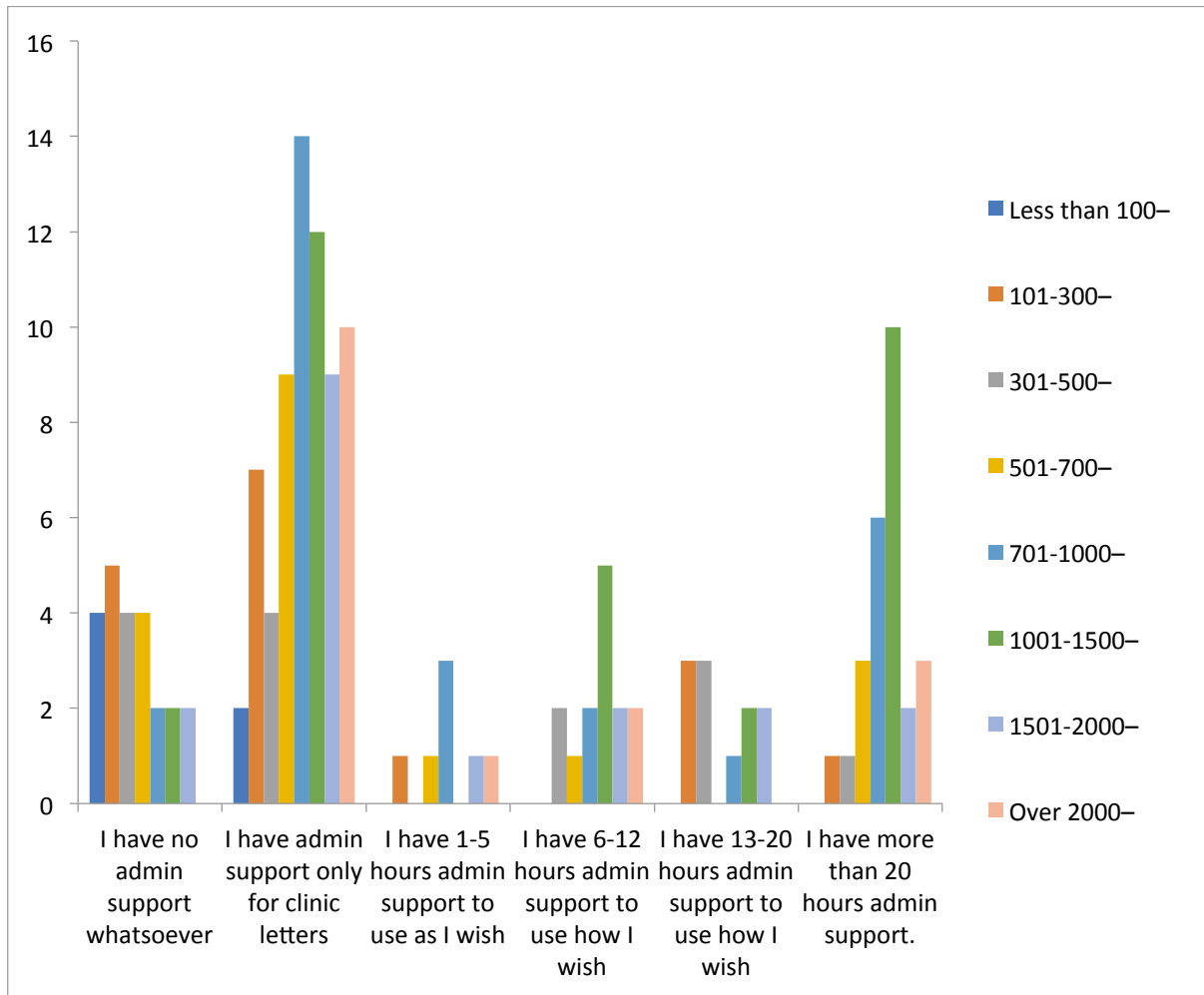
The relationship between caseload and overtime is examined in Figure 15b.

Figure 15b: The relationship between caseload and overtime worked.



The relationship between caseload and admin support is examined in Figure 15c.

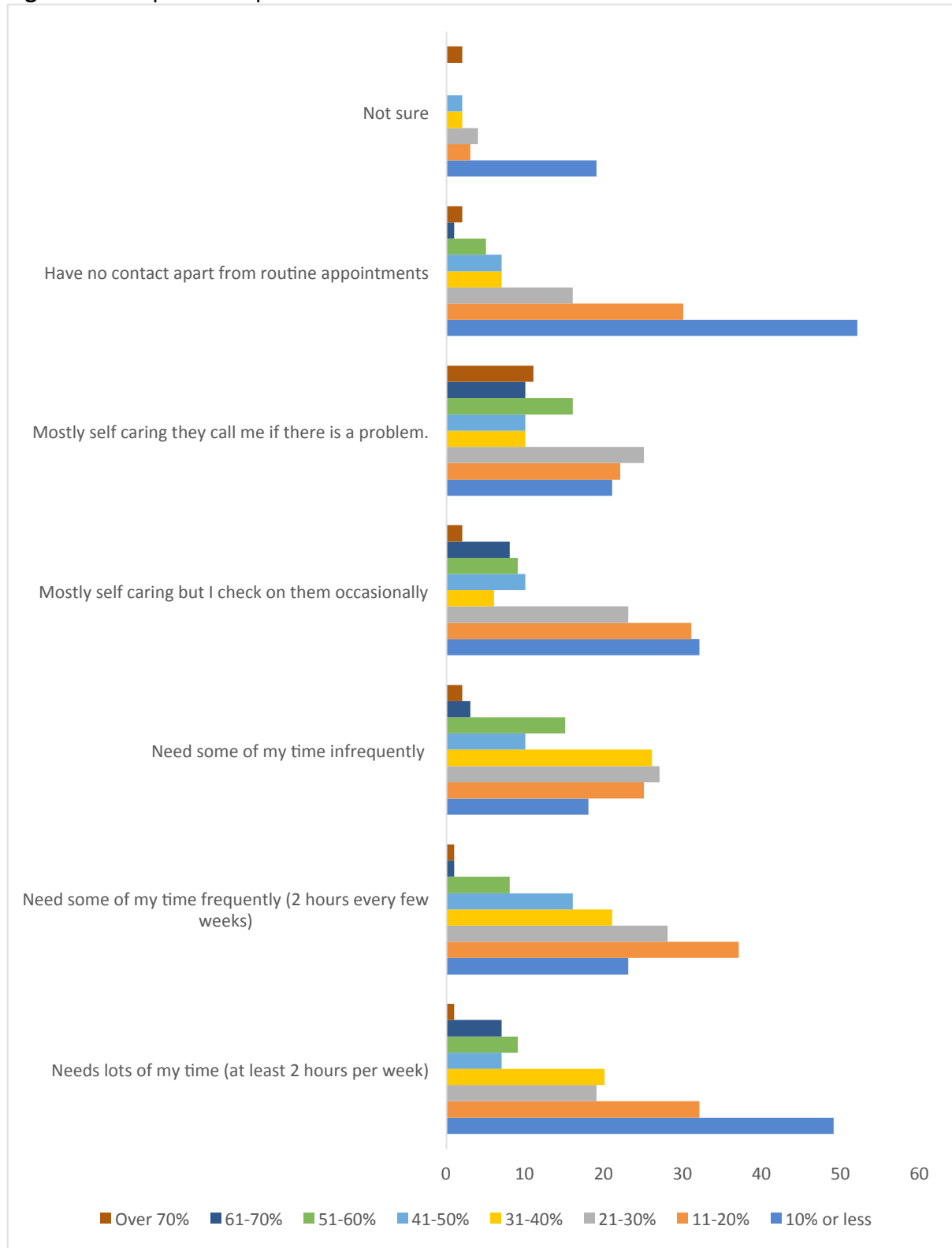
Figure 15c: The relationship between caseload and admin support.



Patient demand

The mix of patients encountered by respondents is summarised in Figure 16. The principle approach is to enable patients to self-manage and respond to crisis proactively.

Figure 16: Respondents patient mix.



Respondents Experience of Working in the MDT

Respondents were generally positive in their experience of working in MDT with 71% agreeing that they work in a functional, supportive and efficient MDT.

Overall the experience of working in the MDT is positive. Only 7% agreed that they worked in a dysfunctional MDT. Satisfaction with MDT working was high in this group compared to others such as prostate cancer where only 45% of respondents in a recent study felt they worked in a functional and efficient MDT and 12% felt they worked in a dysfunctional MDT¹¹. There appear to be some issues around being informed about new patients (the IBD Standards (2013)³ require that all IBD patients should be notified to the IBD CNS) with 53% of respondents agreeing that they were not always told of new patients by other members of the team. As regards constructively challenging other members of the MDT team 70% of respondents agreed that they could challenge all members of the MDT. 29% of respondents would only challenge some members of the team while 36% felt uncomfortable challenging some members of the MDT. These results are summarised in Figure 17.

The free-text responses generally supported the findings above with typical quotes including:

'our MDT works well - discuss patients holistically'

'I am a respected member of the MDT, contribute to all MDT reviews, fully informed of all patients'

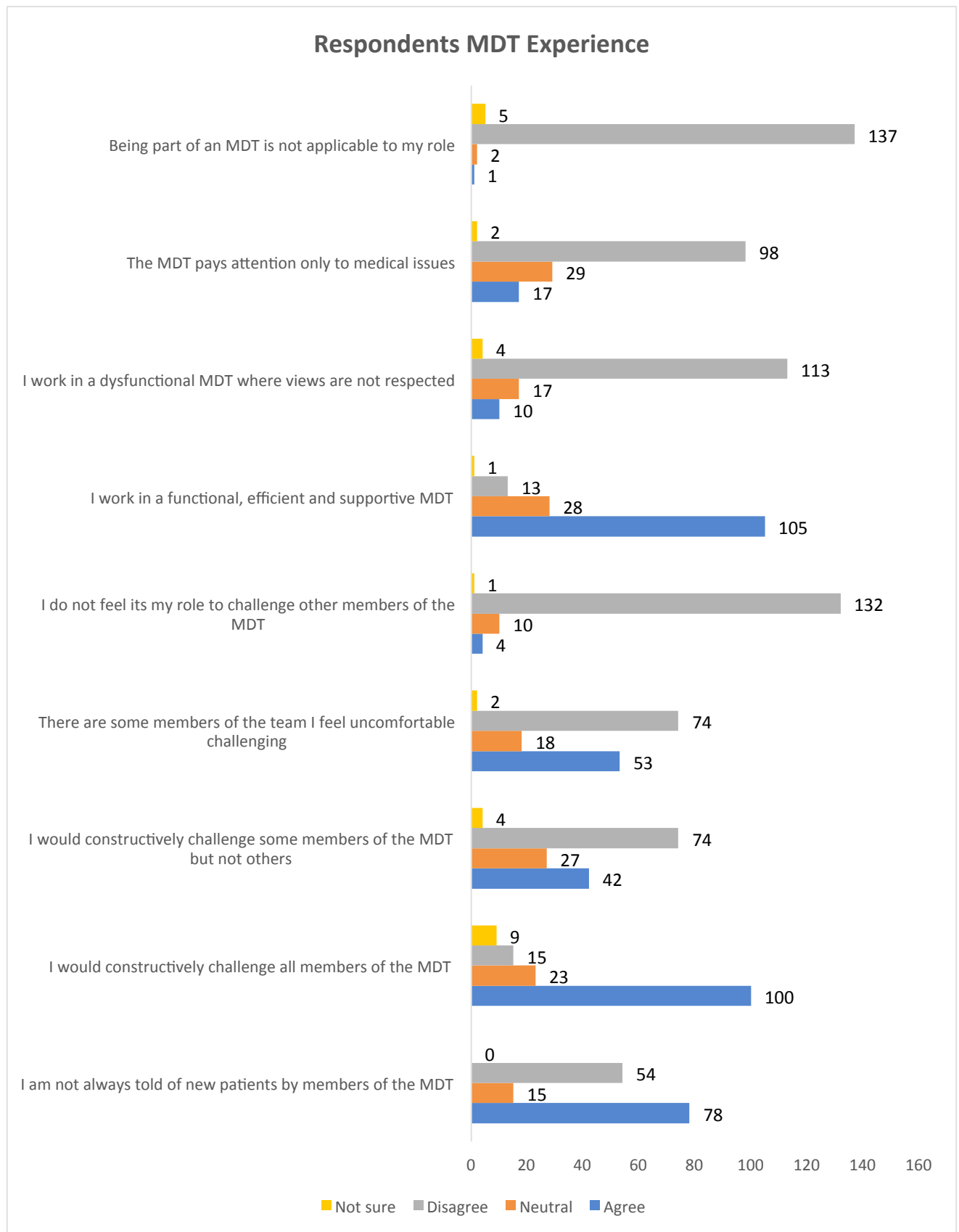
'The MDT is a healthy one where all views are respected'

Some concern was raised regarding the time and resources allocated to the MDT:

'The MDT works well but the time allocated is too short and sometimes can be rushed.'

'An MDT coordinator would be a fantastic asset'

Figure 17: Respondents experience of working in the MDT (148 responses, respondents could choose 'not sure', disagree', 'neutral' or 'agree' to each statement).



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). The responses are summarised in Figure 18a.

It can be seen that as a group IBD specialist nurses 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.

Figure 18a: Respondents work done (134 responses, respondents could choose multiple options).

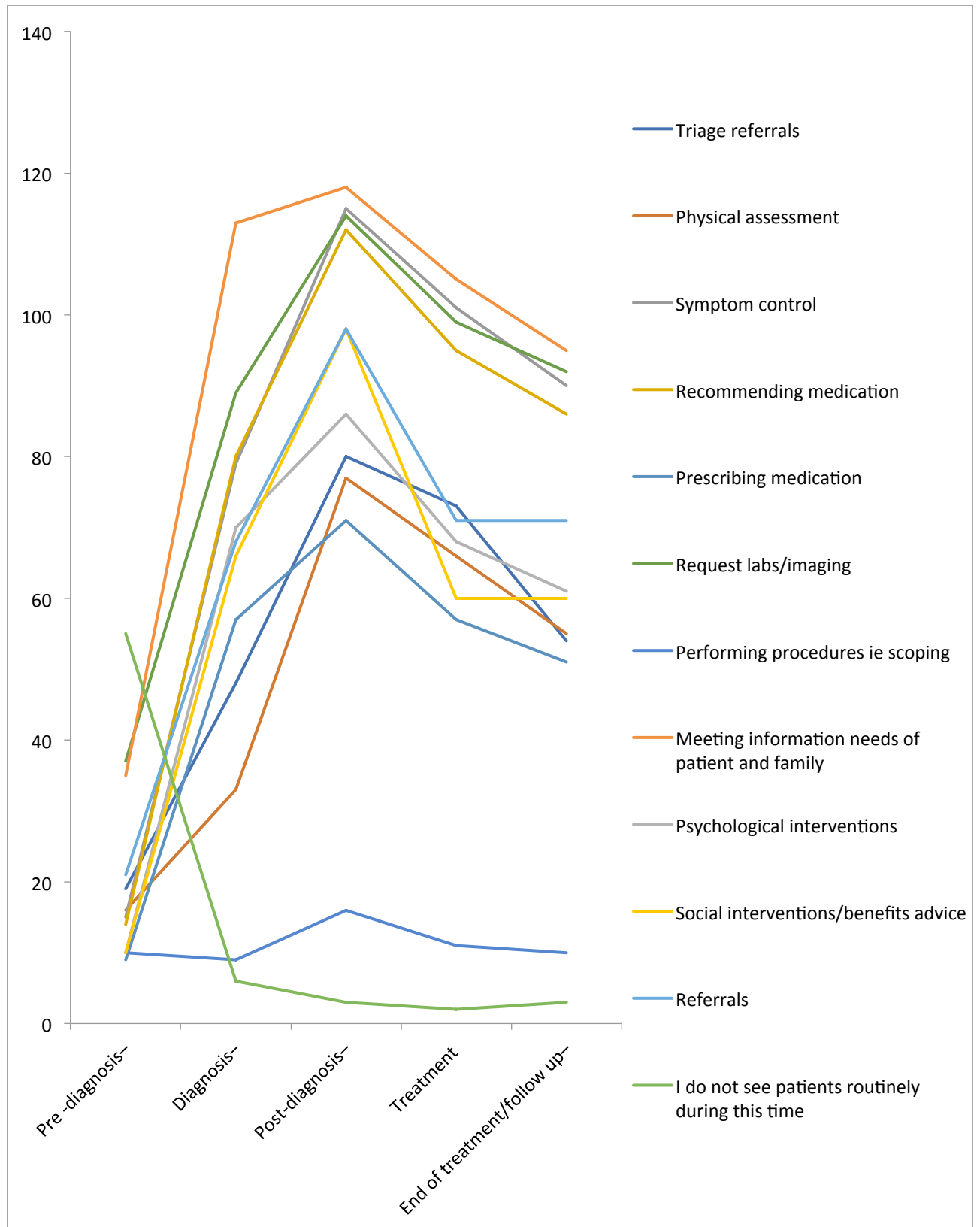


Figure 18b: The six most common interventions at each treatment stage.

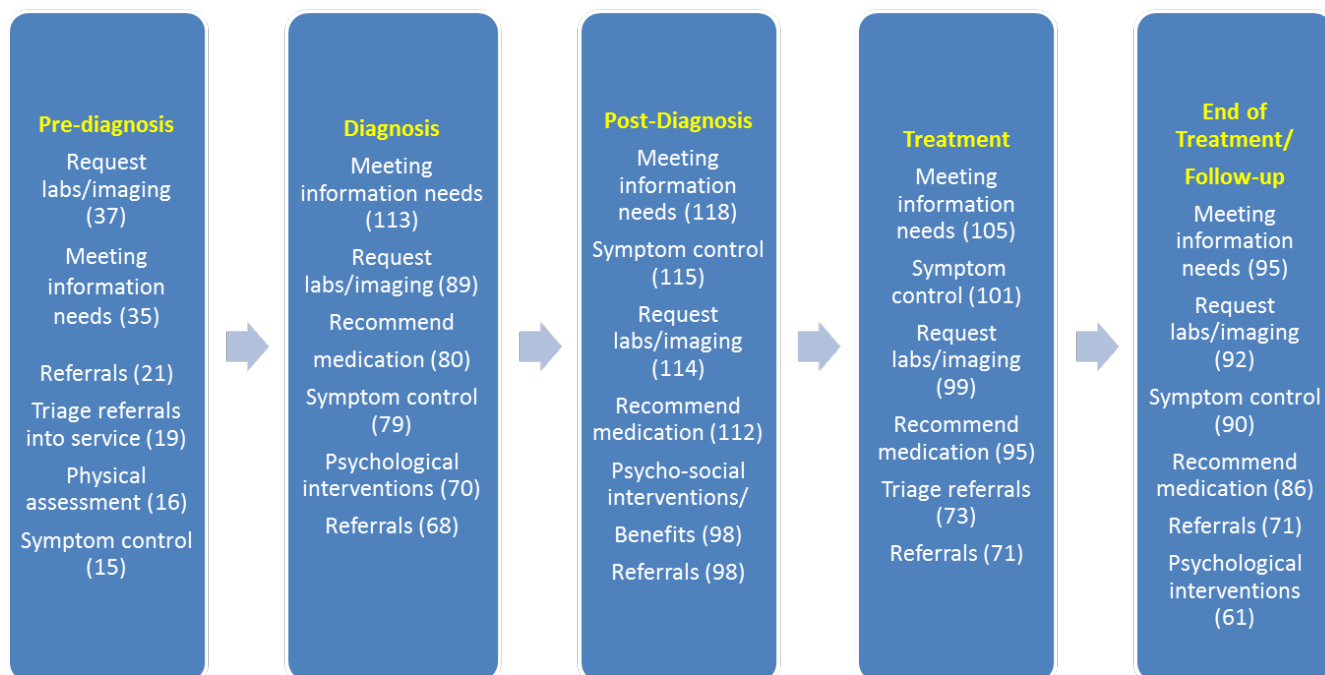
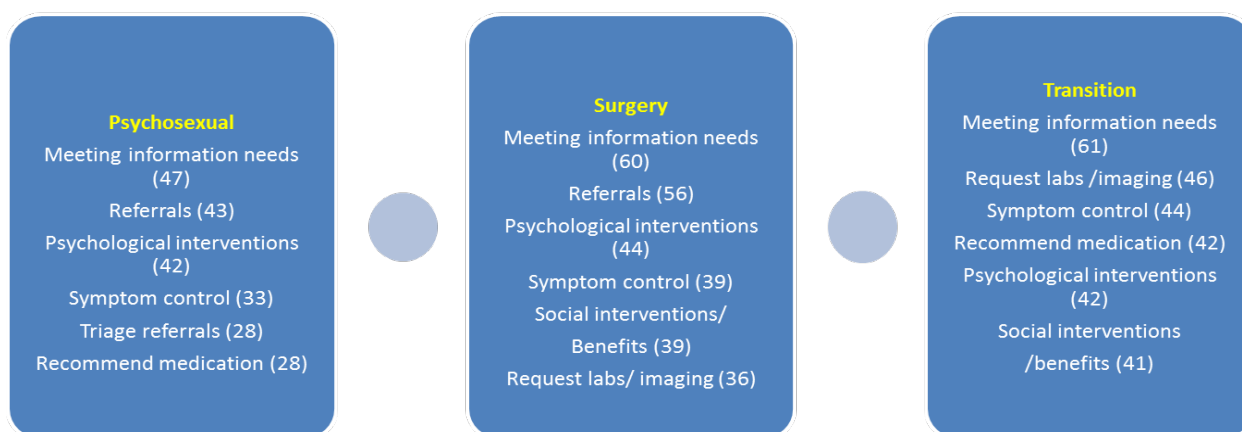


Figure 18c: The six most common interventions for Psychosexual, Surgery and Transition pathways.



79 respondents (59%) were carrying out work at the pre-diagnosis stage. Only 55 respondents (41%) stated that they did not carry out work at the pre-diagnosis stage.

Respondent's Sessional Work

The respondents' work done by session is summarised in Table 2.

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

WORK	SESSIONS
ADVICE LINE	560
NURSE LEAD OUTPATIENT CLINIC	290
INPATIENT WORKING	246
TELEPHONE CLINICS	193
INFUSIONS	142
CONSULTANT LEAD OUTPATIENT CLINIC	121
JOINT NURSE/CONSULTANT CLINIC	78
VIRTUAL CLINIC	78
ENDOSCOPY LIST	36

Provision of an advice line was the most common single use of working time with 85% of respondents spending at least three sessions a week on the advice line and a total of 560 (31% of the total reported sessions) sessions being spent by all respondents.

Nurse lead outpatient clinics accounted for a further 290 sessions, more than twice the number of Consultant lead outpatient clinics at 121 sessions.

Endoscopy does not appear to be common with only 36 sessions being reported.

Respondent's Work left Undone

Across all stages of treatment psychological interventions feature highly in respondents work undone and are the most common work undone at each stage after pre-diagnosis. The IBD Standards Report (2013)³ 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. 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 Figures 19a and b.

Figure 19a: The six most common areas of interventions left undone at each stage of the treatment pathway.

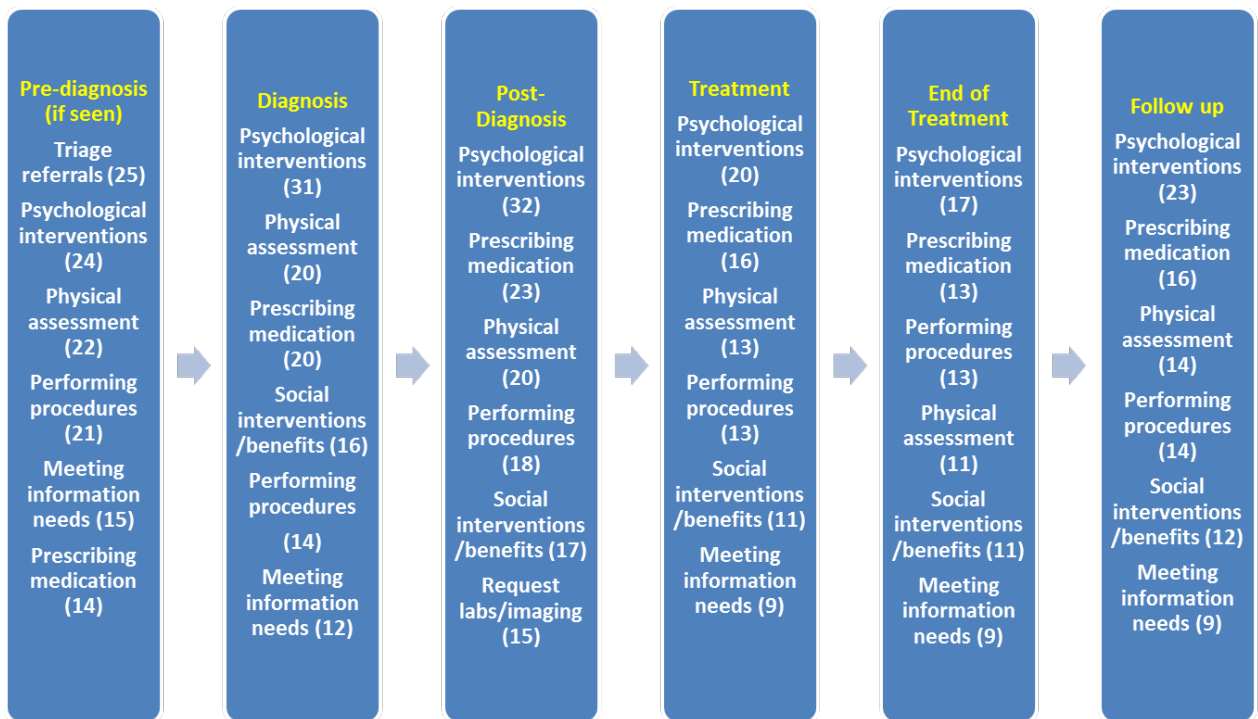
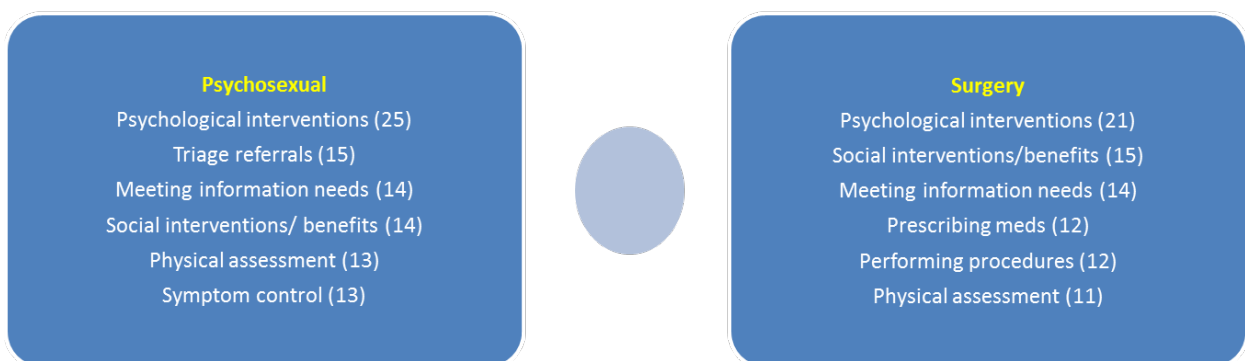


Figure 19b: The six most common areas of interventions left undone for the Psychosexual and Surgery phases of care.



Summary of findings from workload analysis.

- 164 responses were received from IBD CNS to the data collection questionnaire representing a 55% response rate.
- The majority of responses were from England (76%) and responses were received from all four countries of the U.K.
- Most respondents covered either a single (60%) or two (25%) hospital sites.
- 38% of respondents had 3 years or less experience working with IBD patients with the remaining 62% having four years plus experience (32% had over ten years' experience).
- 90% of the responding CNS were working solely in the IBD area of practice. 82% reported spending 80% to 100% of their time on IBD. Just over half (51%) worked with adult and transition patients.
- 72% of respondents worked full time (36 to 37.5 hours per week).
- 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 per week.
- The most common job title reported was 'Clinical Nurse Specialist'.
- Grade 7 was by far the most common grade for respondents (65%)
- 61% of respondents received either no admin support or support for clinic letters only.
- The number of unfilled posts reported by respondents is estimated to be equivalent to 24.5 FTE. No respondents reported frozen posts.
- 43% of respondents had a prescribing qualification. Access to education was high with 82% reporting that they were or had participated in CPD/education within the last 12 months.
- 63% of respondents had a higher caseload than the recommended level. Caseloads as high as 2000 patients plus were reported.
- Respondents generally had a positive experience of working in an MDT and were able to advocate for their patients in the MDT meeting.

- Respondents were involved in all stages of the patient pathway from pre-diagnosis to end of treatment/ follow-up.
- Meeting information needs, symptom control and requesting labs/imaging were the most common tasks carried out by respondents.
- Psychological interventions, prescribing medicines and physical assessment were the most common areas of work left undone reported by respondents.

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