



Royal College  
of Nursing

# Inflammatory bowel disease nursing

Results of an audit exploring the roles,  
responsibilities and activity of nurses with  
specialist/advanced roles



# Acknowledgements

## Authors:

Isobel Mason, Nurse Consultant, Gastroenterology

Karen Holbrook, CNS Gastroenterology

Karen Kemp, NIHR Doctorate Research Training Fellow/Lecturer (research) and Nurse Practitioner Gastroenterology

Vikki Garrick, Paediatric Inflammatory Bowel Disease Nurse Specialist

Kerrie Johns, CNS Gastroenterology

Mary Kane, Stoma Care/IBD CNS

## Regional Champions

Lyndsey Cross, Irene Dunkley, Lyn Dyer, Nicky Fisher, Aileen Fraser, Sharon Gethins, Alex Hall, Heather Hart, Emma Howie, Marie Jerrison, Chris Kelly, Melanie Love, Helen Ludlow, Sheila Mair, Suzanne McGonnall

We would like to thank all those who have been involved in the audit, and in particular we would like to recognise:

The staff at the Royal College of Nursing

Shire Pharmaceuticals



Shire Pharmaceuticals Limited provided the funding for this audit project, but had no control or influence over the content.

---

## RCN Legal Disclaimer

This publication contains information, advice and guidance to help members of the RCN. It is intended for use within the UK but readers are advised that practices may vary in each country and outside the UK.

The information in this publication has been compiled from professional sources, but its accuracy is not guaranteed. Whilst every effort has been made to ensure the RCN provides accurate and expert information and guidance, it is impossible to predict all the circumstances in which it may be used. Accordingly, to the extent permitted by law, the RCN shall not be liable to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by what is contained in or left out of this information and guidance.

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

© 2012 Royal College of Nursing. All rights reserved. Other than as permitted by law no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers or a licence permitting restricted copying issued by the Copyright Licensing Agency, Saffron House, 6-10 Kirby Street, London EC1N 8TS.

This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

# Contents

Foreword	4
Executive summary	5
Methodology	6
Results	7
Part I IBD nurse profile	7
Part II Service profile	9
Part III Audit activity	13
Discussion and recommendations	15
Conclusion	18
References	19

# Foreword

The Royal College of Nursing (RCN) Inflammatory Bowel Disease Network was established as a subsection of the RCN Gastrointestinal Nursing Forum in 1994. The group provides national and local networking to nurses working with inflammatory bowel disease (IBD) patients across the UK.

Nationally, the value of specialist nursing posts in caring for patients with long-term conditions is well recognised (RCN, 2010). Audit work within the IBD specialty has illustrated the quality indicators provided by an IBD nurse specialist (Nightingale, 2000; Pearson, 2005; Kemp, 2009). However there remains a paucity of real data to support the role.

In 2009 South Bank University published a systematic review of the effectiveness of the IBD nurse specialist (Woods, 2009). The main recommendations from the systematic review were:

- to identify a common set of skills, knowledge and competencies required of IBD nurse specialists
- to identify the educational preparation necessary for IBD nurse specialists and their ongoing training and development needs
- to carry out a scoping exercise to identify the number of IBD nurse specialists currently in post, their scope and model of practice, and the contexts in which they operate
- for prospective, rigorously designed studies, exploring the clinical and cost effectiveness of the IBD nursing role.

In response to the systematic review, the RCN IBD group published the first role descriptives document for the role of the IBD nurse specialist (RCN, 2007). This document provides a guide to the development of best practice both for IBD nurses and for local organisations implementing a service.

The descriptors are divided into two sections. The first part reflects the generic qualities required of nurses in the specialty. The second part describes the specialist skills needed to deliver an IBD nursing service. All are linked to knowledge and skills frameworks.

In 2009 the RCN Gastrointestinal Nursing Forum contributed to the first multidisciplinary standards for IBD care (IBD Standards Group, 2009). These standards defined the requirements, in terms of staffing, support services, organisation, patient education and audit, required to provide high quality IBD services.

The standards recommend that the IBD team should include a minimum of:

- 1.5 whole time equivalent (WTE) clinical nurse specialists with an identified role and competency in IBD per 250,000 population.

They also describe the fundamental need for a multidisciplinary approach to IBD patient care, and identify many aspects of the IBD nursing services as essential.

Successive national audits of general IBD care have been carried out by the Royal College of Physicians across all acute NHS trusts within the UK (RCP 2008; RCP 2010). These have shown there has been a significant increase in the number of IBD nurse specialists providing IBD nursing care in the UK. In 2008 61% of acute trusts had an IBD nurse specialist, increasing to 83% in 2010. However, despite the increase in numbers, 79% (150/202) of sites failed to meet the standard of 1.5 whole time equivalent (WTE) per 250,000 population. The audits however, have not looked at the IBD nursing role in any greater depth.

## Aims of this IBD nursing audit

- To evaluate IBD nursing services and identify areas for improvement.
- To provide national evidence of IBD nurse numbers, activity and effectiveness.
- To provide direct feedback to individual nurses and their managers to show local impacts of the IBD nursing service.

This report provides the results of the first national audit of IBD nursing roles, based on the RCN's roles descriptive document. The audit was carried out by the RCN Gastrointestinal Nursing Forum in 2011.

# Executive summary

Demonstrating the value and contribution of specialist IBD nursing has been identified as an essential goal for some time (Woods, 2009). This audit provides the first national data set that shows the enormous contribution IBD nurses are making to the patient experience.

240 IBD nurses across the UK were identified across all four UK countries. Of those, 198 (82.5%) responded to the audit from 118 different nursing services.

The audit took place in May 2011 and nurses entered data online relating to their professional background, their service and their daily activity.

## Key findings

This report provides preliminary data about the role and activity of IBD nurses and their services. It explores their qualifications and training, clinical responsibilities, including advanced and specialist practice, and interaction with patient groups and with each other. It raises concerns about the support systems, both clinical and academic, in place for IBD nursing roles.

The audit has shown valuable insights into the number of nurses, their role and the numbers of patients having contact with IBD nursing services on a regular basis.

### Influence on patient experience

- IBD nurses are influencing the management of considerable numbers of patients within acute care settings. Over the two week audit period 6,472 calls were taken through telephone advice lines, 3,256 patients were seen in outpatient clinics, 112 inpatients with IBD were reviewed by the nurse specialists and 1,203 patients attended the nursing service for day care treatment.
- Extrapolating daily over a 12 month period the data shows IBD nurses provide 28,980 patient episodes per year.

### IBD nursing role

- The IBD nursing role is primarily based in secondary care.
- IBD nurses come from a mixed background of gastrointestinal (GI) nursing roles, often combining other aspects of GI care with their IBD role.
- There is parity between IBD nurse specialist services with the majority providing education

and telephone services, inpatient and outpatient follow up and, managing biologic services.

- The IBD nursing role is central to complex IBD drug management, with the majority of nurses counselling and screening patients prior to treatment and taking responsibility for monitoring patients on treatment.
- Significant numbers of nurses are carrying out autonomous advanced practice, including running independent nurse clinics and non-medical prescribing.

### Gap between practice and theory

- Most nurses that responded had been employed for less than five years and are in their first role as a nurse specialist.
- Reported levels of formal qualification are disappointing, 45% do not hold a basic level degree, less than 10% have a masters level degree.

### Supporting the IBD nurse specialist role

- WTE (the numbers of nurses in post) fall below recommended levels.
- IBD nurses work on average 33 minutes extra per day. If this overtime were charged for all the nurses in this audit the cost to the NHS would be a minimum of £347,200 per year.
- Two thirds of IBD nurse specialist services are suspended or partially suspended when the IBD nurse specialist is away.
- 70% of IBD nurse specialists do not have clinical supervision.
- Administrative support for IBD nurse specialist services is limited. 16% have to type their own clinic letters and one third have to arrange their own outpatient appointments.

### Audit and research

- Disappointing numbers of nurses undertake audit or original nursing research. Few of those who do have gone on to publish their results.

### Recommendations

Based on the findings of this audit a number of actions and recommendations have been developed to improve the impact and influence specialist nurses can exert over patient experience and the quality of IBD services provided.

The RCN Gastrointestinal Nursing Forum recognises its responsibility to publish and disseminate the experience of the audit and its findings to both its members and wider stakeholder organisations. This will ensure that the key messages for service improvement are heard and acted upon.

The forum also recognises the importance of repeating the audit and the need to focus on quality outcome measures for patients and IBD services and is committed to undertaking this. In addition, the forum is committed to working with stakeholders and specialist IBD nurses to identify the educational and training needs of IBD nurses and to highlight any shortfalls in the provision/funding to meet these needs.

The Royal College of Nursing has identified responsibilities to address. But a number of specific recommendations have been developed for workforce service providers and commissioners of IBD services. These include:

1. Providers and commissioners to review the evidence available on the positive patient and financial benefits of deploying IBD specialist nurses before making changes to posts in response to the current financial climate in the NHS.
2. Commissioners to work with providers to increase the establishment of IBD nurse specialist posts to meet national recommended standards (1.5 WTE per 250,000 population).
3. Providers to review workforce requirements to ensure appropriate cover for IBD nurse specialists' absence for planned and unexpected absence.
4. Providers to review their administrative support for IBD nurse specialists and ensure proper administrative support is factored into service development plans to ensure a higher proportion of specialist nurse time is dedicated to clinical activity rather than administration.
5. Providers and IBD nurses to work together to support effective clinical supervision across IBD nursing roles.
6. IBD nurses to lead the development of more regular regional audit to encourage more consistent measurement of their impact on patient outcomes. This information will be invaluable for commissioners and the public as well as participants in the audit and provides an opportunity to recommend and drive changes to improve patient outcomes.

## Methodology

The audit questionnaire was developed by a task group of six nurses representing adult and paediatric IBD nursing in each UK country.

The audit was aimed at:

**'Any nurse who has a specialist or advanced role caring for patients with Crohn's disease or ulcerative colitis.'**

Nurses were identified through the RCN IBD Network, advertising at appropriate conferences/meetings and in the relevant nursing press.

The audit was designed in three parts, using the IBD role descriptives document as a template for the content.

- Part 1 Demographic of the IBD nurse.
- Part 2 Demographic of IBD nursing service.
- Part 3 Prospective audit of individual nurse activity as performed during 10 working days in May 2011.

In April 2009 the basic data set and collection methodology was piloted amongst 16 randomly selected IBD nurse specialists (including two paediatric nurses). Feedback was given on the data content and ease of completion. Only small adjustments were required.

In collaboration with the RCN, the Questback electronic reporting system was adopted to allow nurses to enter data on line.

Regional champions across the UK were identified to support and encourage data entry by nurses in their local area during the data collection period.

The audit was launched in March 2011 at the British Society of Gastroenterology meetings and went live for data entry in April 2011.

# Results

## PART I: IBD NURSE PROFILE

**Fieldwork date:** 31 March-30 April 2011

**E-mail invites:** 240

**E-mail responses:** 198

**Response rate:** 82.5%

### A. IBD specialist nurse job specifics

- 83.8% (166/198) of IBD nurse specialists work within the adult population, 12.6% (25/198) in paediatrics and 3.5% (7/198) in a mix of both adult and paediatric services. 78.3% (155/198) IBD nurse specialists are working in England, 13.6% (27/198) in Scotland, 5.6% in Wales and 2.5% in Northern Ireland.
- One third (29.8%, 59/198) of IBD nurse specialists are band 6, over half are band 7 (56.6%, 112/198), while one in ten (9.6%, 19/198) work to a band 8a. More than half (54.5%, 108/198) have worked at their current position for up to five years, while a similar proportion (52%, 103/198) have been a specialist role for up to five years. (For more detail see Table 1 below).

**TABLE 1 – NUMBER OF YEARS WORKED IN CURRENT POST/AS NURSE SPECIALIST**

Number of years	Length of time in current post (%/n)	Length of time as a specialist nurse (%/n)
0-5 years	54.5% (108)	52% (103)
6-10 years	32.8% (65)	31.8% (63)
11-15 years	12.1% (24)	12.6% (25)
16-20 years	0.5 (1)	3% (6)
Over 20 years	0.0 (0)	0.5% (1)

- 84.8% (168/198) were employed by a trust with 93.4% (185/198) holding a permanent contract. In most cases (191/198) the IBD nurse specialist post was funded by the NHS. 10% (20/198) were funded from other sources (pharmaceutical companies, research funds or university).
- 41.4% (82/198) of the total respondents worked exclusively in IBD. 39.9% (79/198) worked in gastroenterology, whilst just under a quarter (21.2%, 42/198) were nurse endoscopists. (For more details see Table 2 below.)

**TABLE 2 – OTHER CLINICAL RESPONSIBILITIES BESIDES IBD**

Other clinical responsibilities	(%)	(n)
Work exclusively with IBD	41.4	82
Gastroenterology	39.9	79
Nurse endoscopist	21.2	42
Hepatology	15.7	31
Research nurse	7.6	15
Clinical shifts on wards	5.6	11
Stoma care	3.5	7
Endoscopy nurse	1.5	3

- Half (99/198) of respondents had been asked to undertake clinical shifts on a ward in addition to their role. 5.6% (11/198) of the IBD nurse specialists have carried out clinical shifts on wards.

### B. Nursing education

- More than a quarter of all IBD nurse specialists do not hold a first level degree (25.8%, 51/198). Less than one in ten IBD nurse specialists hold a masters degree (18/198).
- Two thirds have not completed the IBD module at first degree level. Only 14.1 % (28/198) completed it at masters level.

### C. Non-medical prescribing

- A third (34.3%, 68/198) of IBD specialist nurses were non-medical prescribers.
- More than half (55.1%, 109/198) make decisions to prescribe and treat patients and decide on drug type and dosage. These nurses make decisions regarding topical and oral 5-ASA therapy, whilst a smaller number (39%, 79/198) make prescribing decisions regarding steroid usage.

### D. Managerial responsibilities

- Just under a fifth (19.2%, 38/198) of IBD nurse specialists have line management responsibilities.
- Two thirds of IBD services are wholly or partially suspended in the absence of the IBD nurse (64.6%, 133/198).

### E. Local groups

- The majority (90.4%, 179/198) of the IBD nurse specialists belong to a regional IBD nurse specialist group.
- Approaching half (48.5 %, 96/198) of IBD nurse specialists are members of Crohn's and Colitis UK. Just under half (41.9%, 83/198) are members of the RCN Gastrointestinal Nursing Forum. A similar proportion (39.4%, 78/198) are members of the British Society of Gastroenterology (BSG).

### F. Appraisal process

- One in eight (16.7%, 33/198) IBD specialist nurses have never had an appraisal. 23% of nurses who had had an appraisal had not done so in the last year.

### G. Study-related leave

- On average, IBD nurse specialists spent seven days (range 0-52 days) in the last year, on IBD related study (the 52 days represented a PhD student). Of the seven days, two of these were the IBD nurse specialists' own time (range 0-20 days)

### H. Clinical responsibility

- More than two thirds (70.7%, 140/198) of IBD nurse specialists do not receive clinical supervision.
- The majority of respondents (79.3%, 157/198) are aware of the RCN IBD nurse role descriptor document and two thirds of these stated that it had an impact on their practice.
- Only 12.1% (24/198) of IBD nurse specialists have conducted an original piece of IBD specific research. Just over half (58.3%, 14/24) of this group have published their findings.



## PART II: SERVICE PROFILE

**Fieldwork date:** 14 April-30 April 2011

**E-mail invites:** 198

**E-mail responses:** 118

**Response rate:** 59%

### A. Work place

- Over half (55.9%, 66/118) of IBD nurse specialist services are based in a district general hospital, whilst 41.5%, (49/118) are based in a teaching hospital and 2.5% in other places (paediatric hospital, NHS acute trust, and tertiary referral centre).
- A quarter (22%, 26/118) of IBD nurse specialist services serve a population of up to 250,000, while approaching half (44.9%/53) serve between 250,000 and 500,000 people.
- Half (49.2%, 58/198) of services employ only 0.6-1.0 WTE to deliver the service, while one in seven services have 1.1-1.5 WTE nurses (15.3%/18). Only 16.9% (20) services have the recommended 1-6-2.0 WTE nurses.
- The services provided by the IBD nurse specialist are shown in Table 3 below.

**TABLE 3 – SERVICES PROVIDED BY IBD NURSE SPECIALISTS**

Clinical responsibilities	Clinical responsibilities (%)	Clinical responsibilities (n)
Education of patients & colleagues	100	118
Telephone advice line	99.2	117
Follow up clinics	97.5	115
In-patient support	94.9	112
Developing & defining IBD service	91.5	108
Managing a biologics service	90.7	107
Managing an immunosuppression service	83.1	98
Rapid access clinic	72	85
Transitional care service	50	59
Administering biologics infusion	49.2	58
Domiciliary visits	13.6	16

- IBD nurse specialist services run a combination of clinic types; in parallel with a doctor, independently, and/or in a doctor led clinic. The service may run one or all of these combinations. Nearly half (46.6%, 55/118) of IBD nurse specialist services conduct clinics independently without a doctor in parallel. The majority of services (78%, 92/118) provide clinics with the IBD nurse specialist running in parallel with a doctor. Just under half (41.5%, 49/118) are conducted in a doctor-run clinic with the IBD nurse specialist available to see patients. Nurses may run a combination of all of these types in one week.

### B. IT and administrative services

- Half of responding services (50%, 59/118) stated that they maintained an electronic register of patients with IBD.
- Of those services identified as keeping an electronic database most (91.5%, 54/59) stated that it was the responsibility of the IBD nurse specialist to input data to the register.
- Just under half (40.7%, 48/118) of IBD nurse services have no administrative support.

- 16.1% (19/118) of services stated that they type their own clinic letters with over a quarter (27.1%) stating that they are responsible for organising patient appointments.

### C. IBD local linkages

- 77.1% (91/118) of IBD services had a local Crohn's and Colitis UK group and two thirds (60.7%, 54/89) of IBD nurse specialists attended the meetings.
- Over a quarter (27.1%, 32/118) of IBD services had an established Crohn's and Colitis UK

patient panel with the majority (75%/24) of IBD nurse specialists attending the meetings.

### D. Patient satisfaction survey

- Two thirds (64.4%, 76/118) of services reported that they had undertaken a patient satisfaction survey for the IBD service.

### E. IBD medications

- Table 4 below shows the results for a number of measures regarding the administration of azathioprine, methotrexate and ciclosporin

**TABLE 4 – ADMINISTRATION OF AZATHIOPRINE, METHOTREXATE & CICLOSPORIN**

Measures	Azathioprine (%/n)	Methotrexate (%/n)	Ciclosporin (%/n)
Counselling patients prior to administering medication	71.8% (84)	66.9% (79)	39.0% (46)
Screening patients prior to administering medication	58.5% (69)	62.7% (74)	29.7% (35)
Responsibility for monitoring patients taking medication	53.4% (63)	59.4% (70)	44.9% (53)
Follow patients up when taking medication	72.0% (85)	66.9% (79)	44.9% (53)

- Table 5 below shows the results for measures related to the administration of infliximab, adalimumab and certolizumab.

**TABLE 5 – ADMINISTRATION OF INFlixIMAB, ADALIMUMAB & CERTOLIZUMAB**

Measures	Infliximab	Adalimumab (%/n)	Certolizumab (%/n)
Co-ordinating funding for the drug	38.5% (45)	40.9% (47)	37.5% (3)
Counselling patients prior to administering medication	85.3% (99)	86.0% (98)	62.5% (5)
Screening patients prior to administering medication	76.7% (89)	78.3% (90)	50.0% (4)
Prescribing the medication	19.8% (23)	22.3%(25)	12.5% (1)
Administering the medication	29.8% (34)	35.4% (40)	62.5% (5)
Monitoring patients taking medication	70.7% (82)	76.3% (87)	62.5% (5)
Following patients up when taking medication	59.8% (70)	59.1% (68)	N/A

### F. Information leaflets and protocol/guideline

- The top information leaflets which IBD nursing services provided to their patients were: Crohn’s and colitis UK introductory

packs (90.7%, 107/198), Abbott Adalimumab information packs (77.1%, 91/198), Schering-Plough Infliximab information packs (69.5%, 82/198), locally written patient information leaflets (61%, 72/198) and Proctor and Gamble (P&G) 20 questions leaflet (49.2%, 58/198).

**TABLE 6 – TOP INFORMATION LEAFLETS PROVIDED BY IBD NURSES TO PATIENTS**

Services provided	(%)	(n)
NACC introductory packs	90.7	107
Abbot Adalimumab information pack	77.1	91
Schering-Plough Infliximab information packs	69.5	82
Locally written patient information leaflets	61.0	72
P&G 20 Questions Leaflet	49.2	58
Core leaflets	29.7	35
NACC family pack	29.7	35
NACC transitional care leaflet	22.9	27
Dr. Falk information leaflets	16.9	20
Ferring IBD Club leaflet	15.3	18
CICRA parent and patient booklet	11.9	14
VSL3 Ferring information leaflet	4.2	5

- A written protocol or guideline was present for the following medication: infliximab (90.7%, 107/198), azathioprine and/or mercaptopurine (82.2%, 97/198), methotrexate (71.2%, 84/198), adalimumab (67.8%, 80/198) and ciclosporin (47.5%, 56/198).
- A written patient information leaflet was in place for the following medication: azathioprine and/or mercaptopurine (97.5%, 115/198), infliximab (97.5%, 115/198), methotrexate (95.8%, 113/198), adalimumab (94.1%, 111/198).
- There were shared protocols for two medicines, namely: azathioprine and/or mercaptopurine (60.2%, 71/198) and methotrexate (33.9%, 40/198).

## G. Internal and external education-related activities

- The main in-house education activities which the services conducted were :

**TABLE 7 – IN-HOUSE EDUCATION ACTIVITIES**

Services provided	In-house education activities(%)	In-house education activities (n)
Informal teaching on the ward	71.2	84
Student nursing	68.6	81
One-to-one on the ward	62.7	74
Medical staff teaching	33.1	39
Formal teaching on the ward	25.4	30
Allied health professional teaching	21.2	25
None	4.2	5
Other (please specify)	16.1	19

- The main external education activities which services carried out are shown in detail in table 8 below.

**TABLE 8 – EXTERNAL EDUCATION ACTIVITIES**

Services provided	External education activities(%)	External education activities (n)
Stand alone study day	19.5	23
Study days or courses run from the hospital	15.3	18
National/International courses	14.4	17
Study day or courses run from the university	11.9	14
None	57.6	68
Other (please specify)	8.5	10

## H. IBD audits

- Over half of services (58.5%, 69/118) had not conducted local IBD audits.
- The highest rated IBD areas in which the audit took place were: the telephone advice line (44.9%, 22/49), managing a biologics service (44.9%, 22/49); and, follow-up clinics (36.7%, 18/49).
- The services who had conducted local IBD audits disseminated the information within the department (81.6%, 40/49), trust wide (34.7%, 17/49), at local NACC group meetings (8.2%, 4/49), nationally (8.2%, 4/49), and internationally (8.2%, 4/49).

## PART III: AUDIT ACTIVITY

**Fieldwork date:** 9 May-22 May 2011

**E-mail invites:** 198

**E-mail responses:** 124

**Total number of entries:** 984

**Response rate:** 62%

### A. In-patient face-to-face patient contact

- A total of 112 in-patients were seen by all respondents daily across the 10 day survey period. An approximate total of 45 hours were spent with inpatients by all respondents per day over the 10 day survey period.

### B. Telephone contact with patients

- A total of 6,472 phone calls were made to the respondents during the audit period.
- 123 hours were spent daily on work-related calls during the audit period and a total of 647 patients/carers/family members were dealt with daily by telephone during the audit period.

### C. Email contact with patients

- A total of 899 emails received and 653 emails sent on a daily basis during the audit period.
- 188 patients/carers/family members were communicated with by email daily during the audit period.

### D. Contact with patients

- The number of IBD patients seen in the various types of IBD clinics is shown in Table 9 below:

**TABLE 9 – TYPE OF CONTACT WITH PATIENTS**

Services provided	Type of Contact (n)
Calls made to helpline	6,472
Nurse run clinics with doctors running parallel	1,905
Day cases	1,203
Nurse led clinic without a doctor	639
Doctor run clinics	439
Telephone clinic	343
Immunosuppression clinic	273
Patients seen without a prior appointments	200
Virtual clinic	107
Inpatients	112

- This equates to 28,980 patient episodes per year.
- The average time spent by the IBD nurse specialist on outpatient contacts is 88 minutes per day. This gives an approximate total of 140 hours of outpatient contact by all respondents daily during the 10 day audit period.

### E. Day cases

- 120 day case patients per day were seen by all respondents during the 10 day audit period. This is the equivalent of 60 hours spent daily on this activity.
- On average IBD nurse specialists spend 32 minutes per day attending IBD service related meetings, 2.5 hours per week.

## F. Patient referrals

- A total of 819 referrals were received by the IBD specialist nurses from the multi-disciplinary team (MDT) during the 10 day audit period.

Table 10 shows the types of referrals made to the IBD nurse specialists.

**TABLE 10 – REFERRALS TO IBD SPECIALIST NURSES**

Referral source	Percentage of referrals made (%)	Number of referral cases (n)
Gastro team	55.31	453
Ward staff	10.01	82
Surgical team	9.28	76
GPs	8.42	69
Admin staff	6.59	54
Endoscopy units	5.98	49
Other nurse specialists	4.15	34
Dieticians	2.69	22
Pharmacists	1.71	14
Outpatient staff	0.9	8
Primary health care professionals	0.06	5
<b>Total no. of referrals received</b>	<b>100.00</b>	<b>819</b>

## G. Working beyond contracted hours

- On average, IBD nurse specialists spent approximately 33 minutes working beyond contracted hours per day (approximately 53 hours daily across the audit period). This equates to £347,200 of unpaid overtime per annum (taking an average Band 6 wage).

## H. Overview of IBD nurse specialists work on a day-to-day basis

- Table 11 below shows, for the first time, the diversity of specialist tasks the IBD nurse specialist undertakes over the two week audit period.

**TABLE 11 – TIME SPENT BY ALL RESPONDENTS PER ACTIVITY PER DAY**

Activities	Average time spent (minutes)	Average percentage of total time (%)
Out-patient contact	87	19.12
Telephone calls	77	17.92
Clinical administration	72	15.82
Day case settings	38	8.35
E-mail contact	38	8.35
Non-clinical administration	37	8.13
Service development	36	7.91
IBD meetings	32	7.03
In-patient contact	28	6.15
<b>Total time spent</b>	<b>455 (7 hrs 35 minutes)</b>	<b>100</b>
<b>Time spent beyond contracted hours</b>	<b>33</b>	<b>N/A</b>

Respondents spent an average of 2.5 hours per day on non-clinical duties.

# Discussion and recommendations

## Response rates

240 nurses were identified as meeting the criteria to enter the audit. The identification process was very thorough, mainly thanks to the effective network group the RCN has developed. It is unlikely that many nurses were missed. An impressive response rate for registration (82.5%) is pleasing and reflects nurses' commitment to the audit. It may also reflect their concerns about job security in respect to recent financial constraints.

Part 2 had a reduced response rate. This was expected as it was only meant to be completed by one nurse per service.

## Influence on patient experience

This audit demonstrates, for the first time, the enormous influence IBD nurses have over large numbers of patients in every area of their hospital experience (outpatients, inpatients, day cases and by telephone).

Whilst individual daily figures in various settings of activity may appear small, the total numbers of patients having contact with IBD nurses is extremely impressive. If the results from the 10 day data collection period were extrapolated over a 12 month period, it would represent a total of 28,980 patient episodes.

IBD nurses take a leading role in making sure patients get the best care possible. Studies in other areas of specialist nursing have shown that, as a substitute for other health care professionals including doctors, specialist nurses are both clinically and cost effective. Studies also show the direct and indirect benefits of specialist nursing roles can include reducing referral times, the length of hospital stays and the risks of patient complications (RCN, 2010).

The NHS is facing one of the toughest financial periods in its history. However, it is essential that every effort is made to protect frontline services and maintain high levels of quality care and patient safety. In previous periods of financial constraint there have been job and service cuts to save money, decisions that in the long-term may well have cost the NHS more than it saved (RCN, 2011). IBD specialist nursing posts are a good example of this, at risk of being the first to be cut even though they have been shown to deliver better patient outcomes, preventative care (which reduce hospital admissions and cost) and high levels of satisfaction (RCN, 2010).

Specialist nursing, as a senior nursing post, is often targeted for cuts because of the higher wages; removing valuable experience and expertise. This data shows the necessity for advanced, autonomous practice. IBD nurse specialists must be recognised as such and cannot be replaced with more junior nursing staff. If down-banding (decreasing pay in order to save money) takes place, it would undoubtedly risk quality of care and patient safety.

These roles contribute enormously to the patient experience and must receive appropriate investment. Organisations must think carefully before changes to posts are made.

## IBD nursing role

The smaller daily activity figures, and the diversity of role titles used, reflect the fact that the majority of IBD nurses also have other GI related roles. Contact with IBD patients may be only a percentage of their patient load.

The data does not identify the percentage of time nurses spend in non-IBD related work, and there is concern that other GI related working may water down their commitment to IBD patients. It may also have an impact on their level of practice, if they are not entirely focused on IBD care. Further investigation is needed of what proportion of roles are spent with IBD patients and whether the proportion correlates to expertise within the specialty.

Analysing the IBD nursing role in detail illustrates the great similarities in practice – emergency telephone contact and advice, patient information and support, counselling, monitoring and administration of immunosuppressive and biological therapies.

It is clear that the RCN's role descriptive document is well used and reflects what most IBD nurse specialist services clinically provide.

Activity appears to be centred in acute hospital settings, reflecting a different service model to other chronic diseases. Only small numbers of nurses are carrying out domiciliary visits and none report working in primary care. However, telephone advice services and the development of shared care guidance show that the IBD nurse specialist is often the link between primary and secondary care.

The audit shows significant activity, but does not measure the quality or the impact of services on patient outcomes. Further prospective, rigorously designed studies are required to measure this.

### The gap between practice and theory

The combination of a relatively inexperienced group of nurses and poor qualification standards is concerning. Most respondents have been employed for less than five years and are in their first role as a nurse specialist. This is considerably less experience than has been found in previous surveys of nurse specialists (RCN, 2005a). Despite this, many are carrying out advanced practices; seeing patients independently in the outpatient setting, making decisions to prescribe and recommending medication adjustments. These are clearly roles that can not be filled by generalist nurses but require advanced nursing knowledge and skill. Only a third hold the non-medical prescriber qualification.

Whilst there are plans to regulate advanced practice roles (NMC, 2011) there are no current nationally accepted standards for preparation for such roles. The Nursing and Midwifery Council (NMC) has previously recommended that specialist practitioners have completed a programme of preparation that is no less than first degree level (NMC 2001). 25.8 % (51/198) of respondents do not meet these minimum standards.

It appears that respondents receive good levels of annual study time from their employers and that levels of regular appraisal are reasonable (81.3%). This support does not translate into the recognisable nursing qualifications that are recommended for this level of working.

Previous review of advanced nursing practice has suggested that time constraints and lack of appropriate cover in the absence of nurses are common barriers to education (RCN, 2005a).

The causes within the IBD setting are likely to be multifactorial. They may include; problems identifying funding sources for these courses, poor quality of appraisal and therefore support at a local level for nurses educational needs, difficulties accessing courses that are local and fit into working schedules, poor knowledge amongst IBD nurses of course availability and a lack of confidence from individual nurses about their academic ability.

IBD nurses must consider their formal qualification requirements when taking on new roles. Employers too must ensure that appraisal addresses training needs and that funding is available for course costs and for the provision of cover in the nurse's absence.

It is vital that IBD nursing educators and providers examine the provision of courses for suitability and uptake and address nurse's needs, both clinically and professionally.

### Supporting the IBD nurse specialist role

Whilst it is recognised that the numbers of IBD nurses across the UK are increasing (RCP, 2010) the data shows there is still a shortfall compared with national guidance.

IBD nurses are working on average 30 minutes extra per day. If this were extrapolated over a 12 month period, it would show an overtime cost to the NHS of 126 hours 33 minutes per nurse per year. Based on the average Band 6 nursing salary this, if charged, would be a cost of £2,800 per nurse per year, or £347,200 for all the nurses taking part in the audit.

Clinical cover for IBD nurse specialists appears limited with the majority of services suspended or partially suspended during their absence. This results in a piecemeal service and a reduction in quality. The suspension presents a risk to patient care and a source of stress on the IBD nurse specialist and other members of the multidisciplinary team.

Organisations must acknowledge the risk suspension of service presents and address staffing appropriately. This is supported by similar statements in the *National standards for IBD care* (IBD Standards Group, 2009).

There are disappointing levels of administrative support with respondents averaging 2.5 hours of non-clinical work per day. 40% of respondents had no administrative support at all. This is supported by other studies showing that nurse specialist time is distracted by undertaking unnecessary administration (typing letters, data entry etc.) (Leary, 2010).

The need for effective administrative support for nurse specialist roles has been identified previously (NHSBSP, 2008; RCN, 2005b).

It is imperative that organisations review the provision of administrative support to current



posts immediately. Administrative support must also be factored into any business case for a new nursing role, just as it would be for new medical services. Clearly, allocating this administrative work to more suitable staff would result in a significant cost reduction and improved quality of service.

The provision of reflective practice and effective nursing clinical supervision has been identified as an essential part of the establishment of a nurse specialist post (NHSBSP, 2008; RCN, 2005b). It is an essential part of clinical governance, particularly in relation to advanced practice. Nurse specialists often work in isolation from other nurses at their level, and need structure and guidance to reflect on the complex and often challenging nature of their clinical role. Advanced practice is acknowledged as challenging role boundaries and necessitating nurses to make decisions outside clinical guidelines or protocols. Without clinical supervision and mentorship from suitable supervisors with appropriate insight into the role, this can lead to significant risk.

The RCN IBD nursing network is clearly influential, with the majority of respondents meeting and communicating with their peers at a local level. Providing formal clinical supervision through this network would be an appropriate extension of this network's role.

### Audit and research

The results show that some nurses carry out local audit, although just under half of all nurses (41%) had not, despite it being a core part of the *RCN Role descriptives document* (RCN, 2007). This work is often only disseminated locally within the department and very little ever reaches the public domain in terms of journal publications. This supports the results of the systematic review of IBD specialist nursing carried out by Woods et al. (2009).

The reasons for this are multifactorial, but are likely to be linked to the low levels of confidence, experience and qualification of many IBD nurses as previously discussed.

It is encouraging to see that two thirds of IBD nurse specialists carry out patient satisfaction audits to promote quality and service development. The data do not assess the impact of these or whether they have been used to improve patient outcomes.

Nurse managers, educators and clinical leaders have a vital role in supporting nurses to develop their confidence and skills in this area.

The RCN IBD Network also has an important role in assisting in the skills development and promoting the sharing and dissemination of such work. The regional networks should be collaborating together to support effective audit and publication should be underpinned through national education programmes.

### Future Audit and Research

This audit provides the initial data to support the IBD nursing role and has highlighted many important issues.

Local results will be provided to participants and their nurse managers along with the opportunity to 'action plan' and recommend/implement change within their local area to improve standards.

The RCN Gastrointestinal Nursing Forum recognises its responsibility to disseminate further the findings of the audit to wider stakeholder organisations to ensure that the key messages for service improvement are heard and acted upon.

It does, however, only 'scratch the surface' when providing evidence for the role. It is recommended that the forum undertake further audit showing the impact on patient outcomes, quality measures and cost effectiveness.

# Conclusion

The results from this audit demonstrate the very significant activity being carried out by IBD nurses across the UK.

Their roles are exclusively based in secondary care, providing some links into primary care. Most IBD nurse specialists have other gastrointestinal nursing roles, but the results show that the IBD nursing services provided are similar and follow the *RCN Role descriptives document* (RCN, 2007).

Clinical roles include areas of advanced practice, including nurse run clinics and non-medical prescribing. Most nurses have a fundamental role in providing complex medical management.

The majority of IBD nurse specialists have been in post for less than five years and are in their first specialist nursing role. There are low levels of formal qualification despite good study leave allocation and reasonable appraisal processes.

The number of IBD nurses in post are increasing but still fall short of the recommended level. Those nurses identified work considerably longer hours than contracted and have poor levels of clinical supervision. There are poor levels of administrative support. Nursing services are often suspended, or partially suspended, when the nurse is away.

All IBD nurses provide education and support to patients within their service and have good links to patient groups.

The audit has recommended several vital further projects to address some of the more concerning results identified; particularly a review of education and training needs and a further national audit to consider the quality of patient experience in relation to IBD nursing services.

This report provides a valuable insight into the current numbers, activity and competency of IBD nurses, a group of nurses with increasing influence over the patient experience and service development within the specialty.

This information should help to inform providers, commissioners, directors of nursing and nursing managers, professional colleagues and patient groups when planning a high quality IBD service.

# References

- IBD Standards Group (2009) *Quality care service standards for the healthcare of people who have inflammatory bowel disease* Oyster Healthcare Communications Ltd.: Brighton. [www.bsg.org.uk/attachments/160\\_IBDstandards.pdf](http://www.bsg.org.uk/attachments/160_IBDstandards.pdf) (accessed 16 Jan 2012).
- Kemp K, UK IBD Audit Steering Group (2009). "UK Inflammatory bowel disease audit: nurse correlations between 2006 and 2008." *GUT* 59, Suppl 1(4): A39.
- Leary A, Oliver S (2010) *Clinical nurse specialists: adding value to care*, RCN Rheumatology Forum: London. Publication code 003 598. [www.rcn.org.uk/publications](http://www.rcn.org.uk/publications)
- Nightingale A, Middleton W, Middleton SJ, Hunter JO (2000) Evaluation of the effectiveness of a specialist nurse in the management of inflammatory bowel disease, *European Journal of Gastroenterology & Hepatology*, 12.
- NHSBSP (NHS Breast Screening Programme) (2008) *Quality assurance guidelines for clinical nurse specialists in breast cancer screening*, Publication No. 29, 4th edition. <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp29.pdf> (accessed 16 Jan 2012)
- Nursing and Midwifery Council (2001) *Standards for specialist education and practice*, London: NMC. <http://www.nmc-uk.org/Educators/Standards-for-education/Standards-for-specialist-education-and-practice> (accessed 16 Jan 2012).
- Nursing and Midwifery Council (2011) *Regulation of advanced nursing practice*, London: NMC. <http://www.nmc-uk.org/About-us/Policy-and-public-affairs/Politics-and-parliament/PMs-Commission-on-the-future-of-nursing-and-midwifery/Regulation-of-advanced-nursing-practice/> (accessed 16 Jan 2012)
- Pearson, C (2005) Development of a rapid access service for patients with exacerbating inflammatory bowel disease, *Developing Practice Improving Care*, 3-4.
- Royal College of Nursing (2005a) *Maxi nurses. Advanced and specialist nursing roles*, London: RCN. Publication code 002 756. [www.rcn.org.uk/publications](http://www.rcn.org.uk/publications)
- Royal College of Nursing (2005b) *Competencies: a competency framework and guidance for developing paediatric epilepsy nurse specialist services*, London: RCN. Publication code 002 792. [www.rcn.org.uk/publications](http://www.rcn.org.uk/publications)
- Royal College of Nursing (2007) *Role descriptives for inflammatory bowel disease nurse specialists*, London: RCN. Publication code 003 194. [www.rcn.org.uk/publications](http://www.rcn.org.uk/publications)
- Royal College of Nursing (2010) *Specialist nurses: changing lives, saving money*, London: RCN. Publication code 003 581. [www.rcn.org.uk/publications](http://www.rcn.org.uk/publications)
- Royal College of Nursing (2011) *Frontline First: Protecting services improving care*. [www.rcn.org.uk/frontlinefirst](http://www.rcn.org.uk/frontlinefirst)
- Royal College of Physicians (2008) *UK IBD Audit 2nd Round: National results for the organisation of adult inflammatory bowel disease*, London: RCP.
- Royal College of Physicians (2010) *UK IBD Audit 3rd round: National results for the organisation of adult inflammatory bowel disease services in the UK*, London: RCP.
- Woods L, Belling R, McLaren S. (2009) Specialist nursing interventions for inflammatory bowel disease, *Cochrane Database Systematic Reviews*. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006597.pub2/pdf>



Royal College  
of Nursing

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

**February 2012**

RCN Online  
[www.rcn.org.uk](http://www.rcn.org.uk)

RCN Direct  
[www.rcn.org.uk/direct](http://www.rcn.org.uk/direct)  
0345 772 6100

Published by the Royal College of Nursing  
20 Cavendish Square  
London  
W1G 0RN

020 7409 3333

Publication code: 004 197



Shire Pharmaceuticals Limited provided the funding for this audit project, but had no control or influence over the content