HEALTH AND SPORT COMMITTEE

HEALTH AND CARE (STAFFING) (SCOTLAND) BILL

SUBMISSION FROM Royal College of Nursing Scottish Inflammatory Bowel Disease Nurses Network

About the RCN Scottish Inflammatory Bowel Disease Nurses Network

The aim of the Network is to improve outcomes for patients with Inflammatory Bowel Disease (IBD), by sharing practice and collaborating on service improvement initiatives. The Network is supported by Crohn’s and Colitis UK to maintain and strengthen the links between healthcare professionals and patient groups.

The goals of the Network are to:

- Provide cohesive representation of the IBD Nurse voice across Scotland and raise the profile of IBD Nursing in Scotland.
- Influence IBD Nurse service-provision across Scotland by sharing ideas, principles and best practice.
- Facilitate Scotland-wide nursing research and audit.
- Develop core standards for IBD Nurses in Scotland in line with current IBD Standards.
- Focus on networking, peer support and collaboration.

About Crohn’s and Colitis UK

Crohn’s and Colitis UK is a national charity leading the battle against Crohn’s Disease and Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease (IBD). They provide high quality information and services, support life-changing research and campaign to raise awareness and improve care and support for anyone affected by these conditions.

Crohn’s and Colitis UK believes that the availability of IBD nurse specialists is vital for people living with IBD to be able to access responsive health services and improved clinical outcome.

Specialist IBD nurses play a fundamental role in delivering high quality patient care and experience, lead patient centred service redesign, improve the quality of care and represent excellent value for money.

About Inflammatory Bowel Disease

At least 300,000 people or 1 in 210 people in the UK have Crohn’s Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). Scotland has the highest prevalence of IBD in the UK with an estimated 26,000 people living with this chronic disease. IBD is a lifelong condition that most commonly first
presents in the teens and early twenties (mean age of diagnosis is 29.5 years) and ongoing outpatient care is currently required for the vast majority of these people.

In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue. Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably throughout a person’s lifetime.

The conditions can affect an individual’s ability to work, learn, socialise and form and maintain relationships, often resulting in increased absence from school and education and time away from work. Lifetime medical costs for IBD are comparable to other major diseases such as diabetes and cancer.

**RCN Scottish IBD Nurse Network response**

The RCN Scottish IBD Nurses Network welcomes the opportunity to submit a response to the Health & Sport Committee’s call for evidence on the Health and Care (Staffing) (Scotland) Bill. In this response we have highlighted that it is impossible to guarantee safe and high quality IBD Services if the minimum IBD Clinical Nurse Specialist provision is not met. The now outdated national standard called for 1.5 Whole Time Equivalent (WTE) IBD nurses per 250,000 population i.e. 666 patients per 1 WTE (IBD Standards 2013). Following a piece of work commissioned by Crohn’s and Colitis UK, led by Professor Alison Leary published in the report *Modelling Caseload Standards for IBD Specialist Nurses in the UK (April 2017)* there is a new recommended caseload of 2.5 WTE IBD nurses per 250,000 population (equating to 500 patients per 1 WTE IBD Nurse Specialist). We are currently not close to this staffing level in Scotland.

The RCN Scottish IBD Nurses Network welcomes the guiding principle that services should be arranged (iv) ensuring the wellbeing of staff and (v) being open with staff and service users about decisions on staffing. However, we believe this is not possible without appropriate leadership in IBD nursing and requires the recruitment of nurses into these leadership roles who are expert in both chronic patient management and Clinical Nurse Specialist (CNS) service design and delivery. This is currently not the case and is a significant issue.

To address this, we propose that a comprehensive and effective training programme should be made available to IBD Nurse Specialist staff new to post. In addition to this, a formal career structure for progression into more senior CNS roles should accompany this programme.

For this consultation, we are mainly limiting our responses to Part 2 of the Bill.
Key strengths of part 2 of the Bill

**Part 12IA Duty to ensure appropriate staffing** states that: “It is the duty of every Health Board and the Agency to ensure that at all times suitably qualified and competent individuals are working in such numbers as are appropriate for—(a) the health, wellbeing and safety of patients, and (b) the provision of high-quality health care.

The Network believes that it is impossible to guarantee this until an appropriate career structure for CNS’s exists which includes nationally agreed academic standards and a structure for career progression. Ensuring this standardisation would fit well with the aspirations of the national Transforming Roles Programme which has already standardised [Advanced Nurse Practitioner roles](#).

As stated above, it would also be impossible to guarantee that IBD Nurse Specialists are working in “such numbers as are appropriate” if the 1 nurse per 500 IBD patients caseload is not met. Furthermore, in order to deliver safe management of high cost medicines (i.e. biologics and biosimilar drugs commonly used in IBD), it is also imperative that this safe staffing ratio is met. We believe this Bill provides an opportunity to directly address this shortfall.

Subsection 2 (d) states that the “common staffing method” means that a Health Board must take into account a number of factors including patient needs. We would make the point that IBD is a relapsing and remitting condition which follows a very unpredictable course, therefore requiring a responsive service (e.g. one that provides a range of communication options and the ability for patients to have rapid access to the service during a ‘flare-up’ of their condition).

IBD can place severe limitations on patients’ work, family and social life. Not one disease characteristic is the same, and the presentation of individuals is therefore varied. We welcome the requirement for Health Boards to take into account patient needs and these individual sets of circumstances. We would also highlight the fact that IBD Nurse Specialists deliver a great deal of psychological care due to lack of formal psychology support in place, particularly in adult IBD services.

Subsection 2 (d) also states that that Health Boards must take into account appropriate clinical advice. However, the Network would like to note that CNSs have no ‘direct line’ to their Health Boards to provide ‘appropriate clinical advice’ regarding staffing levels, relying on managers to do this.

We would highlight the report submitted to Scottish Government in April 2017, authored by the Network Chair Vikki Garrick; *Inflammatory Bowel Disease Nursing Services in Scotland: A short report commissioned by the DO- IT Collaboration on behalf of the Scottish Government* (a copy of which is enclosed with this submission). This report illustrates that most Clinical Nurse Specialists are, in most cases, line managed by managers whose priorities lie in managing acute services (wards) and not CNSs. Our clinical concerns, in the main, therefore go unheard due to a lack of appropriate leadership and management structure. Again, there is a significant opportunity with this proposed new legislation to address this issue and to ensure that clinical advice on staffing levels is listened to and acted upon.
**Key weaknesses of part 2 of the Bill**

The Network notes that **12IB Duty to follow common staffing method (subsection 2)** frequently refers to the “guiding principle for health and care staffing”, yet we are unsure what this principle is, where it can be accessed and are therefore unable to comment on its use.

In addition, subsection 2(a) states that:

“(2) The common staffing method means that a Health Board or the Agency (as the case may be)—

(a) uses the staffing level tool and the professional judgement tool as prescribed in regulations under subsection (3) and takes into account the results from those tools.”

The Scottish IBD Nurses Network are unaware of these tools, how they might be used and where to access further information about them. We would like to ask the committee what the current ‘rules’ around the use of these tools are, i.e. how often/when should they be used? We would also ask why this professional network has not been made aware of these tools?

Finally, we would suggest that the definition of Clinical Nurse Specialists in **part 121C Common Staffing Method; types of health care** is incomplete and requires review. It does not reflect the complexity or level of expertise necessary within these roles nor does it represent the range of seniority within this type of health care – namely chronic disease management.

**For further information please contact:**

Nancy Greig, Health Policy and Public Affairs Officer
Crohn’s and Colitis UK (on behalf of the RCN Scottish IBD Nurses Network)
Email: nancy.greig@crohnsandcolitis.org.uk
Tel: 0141 404 0231/ 07738765331
Inflammatory Bowel Disease Nursing Services in Scotland: A short report commissioned by the DO-IT Collaboration on behalf of the Scottish Government.

April 2017
Acknowledgements

Author:

Sr Vikki Garrick RGN, RSCN, BSc, NMP, MSc.
Paediatric Inflammatory Bowel Disease Clinical Nurse Specialist/ GI Clinical Nurse Specialist Team Lead.
The Royal Hospital for Children, Glasgow

Clinical Nurse Specialists interviewed:

Sr Audrey Anderson – NHS Ayrshire and Arran
Sr Judy Nisbet – NHS Dumfries and Galloway
Sr Esther Brash – NHS Fife
Sr Ann Muir and Sr Gillian Richardson – NHS Forth Valley
Sr Colette Fotheringham – NHS Forth Valley
Sr Carol Cameron – NHS Grampian
Sr Laura Gray – NHS Grampian
Sr Lisa Richmond – NHS Greater Glasgow and Clyde
Sr Elizabeth Lightbody – NHS Greater Glasgow and Clyde
Sr Susan Laird - NHS Greater Glasgow and Clyde
CN David Armour – NHS Highland
Sr Therese MacDonald – NHS Lanarkshire
Sr Sue Aitken – NHS Lothian
Sr Julie Fyall – NHS Tayside
Support also given by:

Mrs Jen Rogers, Chief Nurse, Children’s Services, The Royal Hospital for Children, Glasgow

Sr Lee Curtis, Paediatric Inflammatory Bowel Disease Clinical Nurse Specialist, The Royal Hospital for Children, Glasgow

Sr Lisa Richmond, Paediatric Inflammatory Bowel Disease Clinical Nurse Specialist, The Royal Hospital for Children, Glasgow

Isobel Mason, IBD nursing development at Crohns and Colitis UK & Nurse Consultant, Gastroenterology Department, Royal Free Hospital, London
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Foreword

The Delivering Outpatient Integration Together (DO IT) Gastroenterology collaboration was set up in December 2015 to review the delivery of Gastroenterology services across Scotland. Following consultation, Inflammatory Bowel Disease (IBD) was highlighted as an area of significance within this specialty and subsequent to that, specifically, the role and scope of IBD Clinical Nurse Specialist (CNS).

The Royal College of Nursing (RCN) Inflammatory Bowel Disease Nursing Audit (2012) has done this work across the UK, however data on the role and scope of Scottish IBD CNS’s is as yet unclear. Both the National Clinical Strategy for Scotland (2016) and the National Blueprint for Inflammatory Bowel Disease in Scotland (2016) have identified a need to review the current clinical paradigm towards a more proactive approach to patient management with a specific focus on patient education and self management where at all possible.

The importance of the role of the IBD CNS in the provision of proactive care is well documented (IBD audit 2012, RCN IBD Nurse audit 2012, IBD Standards 2013, National Blueprint 2016) and was also highlighted as an area of specific importance in the DO IT workshops carried out in the latter quarter of 2016. The author was approached by the DO IT team in September 2016 to formally scope out the role of the IBD CNS workforce in Scotland. This was done through a series of face to face interviews with nurses from most of the Health Board areas with an IBD CNS in post. Eleven of the fourteen Health Boards had a CNS in post and ten areas were visited (Appendix 1). NHS Borders was not visited due to the limited time available to complete the piece of work.

Aim

To scope out IBD CNS services within the 14 Health Boards in Scotland.

Scope

The scope of the document will include an overview of the IBD CNS Service structure across each Health Board as this has a significant impact on how these services are delivered. For this data, the author liaised with Crohn’s and Colitis UK who recently carried out a UK wide audit capturing CNS service data. Quantitative data for the Scottish nurses was extrapolated from this.
It will also include data from a structured questionnaire designed by the author using a combination of key recommendations and outcomes from the National Blueprint for Scotland (2016) and the RCN IBD Nurse audit (2012). These were used as a template on which to guide the information gathered. Specifically, 2 of the 5 the key recommendations highlighted in the National Blueprint were used. These are:

1) **A responsive IBD service which provides** -

   - Patient advice via email and telephone
   - Expedited patient reviews within one week
   - Teleconsultation clinics and virtual clinics in addition to face to face appointments
   - Specialist IBD Nurse
   - Dedicated IBD Clinics
   - Access to specialist dietetic support
   - Access to pharmacy support

2) **Multidisciplinary (MDT) working which is based on** -

   - Regular MDT meetings
   - A clearly defined MDT
   - Presence of an IBD Nurse

These 2 recommendations were chosen because the detail of each encompasses a significant proportion of the IBD CNS role as identified in the RCN IBD Nurse audit (2012); specifically their role in managing telephone advice lines, running clinics and facilitating rapid patient review. The time sensitive nature of the project (6 months) made it unrealistic to address the other 3 recommendations within the Blueprint: IT support, access to specialist paediatric services (although paediatric nurses were interviewed) or primary care faecal calprotectin.
Additional findings from the RCN audit (2012) shaped the remainder of the questionnaire with specific reference to CNS input in running immunosuppressive and biologic services. This is of particular relevance currently with the introduction of therapeutic drug monitoring and biosimilars into the patient management paradigm. The logistics of starting a patient on biologic therapy requires considerable co-ordination both from a clinical and administrative perspective. As a working IBD CNS, the author also has extensive clinical and managerial experience and is aware that managing biologic services in addition to the components listed above from the National Blueprint document, are still significant parts of the IBD CNS role. For this reason, managing biologic therapy will also be included in the scope of this document.

This report will look at each of these areas in turn with a specific focus on the degree of input by the IBD CNS and will be the first to explore the workings of IBD Nurse Services across Scotland.
Executive summary

Of 14 Health Boards in Scotland, 11 have IBD CNS Services. 61 individual CNS’s representing 11 Health Boards were identified as having an active role in managing patients with IBD (49 Adult, 12 Paediatric). 14 nurses were interviewed, representing 10 Health Boards (Appendix 1). Without exception, all CNS’s nurses interviewed were highly knowledgeable, motivated, enthusiastic, and above all patient focussed. IBD Nurse services in Scotland are dynamic and flexible and at the heart of that is a workforce committed to delivering quality care to the IBD patient group. Specific nurse-led exemplars of practice include:

- NHS Fife – redesigning the patient telephone advice line and setting up telephone clinics to allow more efficient use of time for the patients and the CNS service. Planned calls are now made reducing hospital clinic attendance and time off work/school for the patient.

- NHS Highland – re-designing the MDT meeting process resulting in more efficient and documented meetings with clear and measureable outcomes. The nurse in this service was also awarded the British Journal of Nursing IBD nurse of the year 2017.

- NHS GGC – development of a ‘flare card’ to encourage self management and key fob with IBD nurse contact details so that the patient can attach it to their house keys.

- NHS GGC – development of an IBD nurse email clinic to allow more flexible and rapid access to the IBD CNS service. Email clinics run every day.

- NHS Forth Valley – Patient information leaflet for all new diagnosis giving IBD CNS service contact details and other useful information creating a visible and accessible IBD CNS service. This Health Board also formally collects CNS specific data and is the only Health Board to do this.

- NHS Lothian – redesigning biologic services to set up group counselling sessions for patients starting biologic therapy. This area also has an identified IBD pharmacist who has helped redesign their biologic service. This frees up nurse clinic time for other (more clinically urgent) reviews.

- NHS Lanarkshire and Dumfries and Galloway– using the electronic patient management system to log all advice line calls so that the workload is visible and auditable.
CNS Services

CNS service design is comparable across Scotland with all services running telephone advice lines and the majority of services running nurse led clinics. The detail of how these are run however is not equitable across all Health Boards with significant variability in how activity is recorded. 71% of IBD CNS’s have responsibility for more than just IBD including hepatology, coeliac disease, rheumatology, nutrition and endoscopy with variability in the exact amount of time dedicated (and delivered) to IBD. This makes it impossible to accurately assess if we are meeting the National Standard of 1.5 WTE IBD nurses per 250,000 population (IBD Standards 2013). However, given that 71% of CNS’s have more than one role, this makes it highly unlikely. 78% are managed by Lead Nurses who have additional management priorities – namely the management of acute services and this is the cause of some frustration among the CNS’s in post. More than half (57%) of CNS’s do not have a job plan and although 92% of them receive annual appraisal (when their eKSF is due) very few have any contact with their manager in-between these meetings.

The first task on the National Blueprint for Inflammatory Bowel Disease in Scotland (2016) implementation list is to ‘Develop consensus recommendations on the role and job structure of IBD nurses in IBD services’. This report will demonstrate that IBD nurse roles and job structures are currently unclear and there is some disparity in how IBD nurse services are run across the 10 Health Boards interviewed. Many nurse services are still set up with no clear job plan, no clear service design and no leadership or mentoring to support nurses in these specialist roles. Many posts have morphed into ‘reactive’ posts where the IBD nurse role has developed to ‘fill the gaps’ in the IBD services. Biologic management is a good example of this and the co-ordination and management of this particular aspect of the service has become a significant ‘time stealer’ for many IBD nurses in Scotland. Many aspects of this particular issue could be delegated to admin staff as part of the MDT.

Telephone advice lines

All services run telephone advice lines allowing direct and rapid access to expert advice. There is however significant disparity in how these are run on a day to day basis. The majority of services (64%) pick up calls in an ad hoc manner, frequently between other duties – outpatient clinics, inpatient reviews or endoscopy lists (this list is not exhaustive).
There is no clearly identified and protected time in most services to run the telephone helpline with 78% of advice line calls being picked up and triaged by the IBD nurses themselves. There is no filter for admin calls (such as re-arranging appointments) or ability to signpost (to the GP or other department) when appropriate.

This means the CNS picks up every call regardless of need for clinical input or not. A more standardised approach to this would be beneficial to both the patient and the IBD CNS service. Admin support for telephone advice lines and the implementation of dedicated telephone review clinics would help to address this issue in addition to delivering on the National Clinical Strategy outcome of reducing outpatient reviews at clinic (National Clinical Strategy 2016). Of note, all CNS services commented on how stressful they found the advice line.

**Clinics**

85% of CNS services run nurse led clinics however 34% of these are ‘tagged on’ to a medical clinics where the data is gathered under the medics name. The IBD CNS workload in these cases is thus invisible. 50% of Health Boards interviewed see IBD patients in general GI clinics, although most associated nurse led clinics are IBD specific. 64% of CNS services offer formal rapid access and review although this is not always recorded robustly and not all rapid reviews are nurse-led.

Many nurses demonstrate innovative use of nurse-led clinic slots with examples such as education on self management, disease and drug education, implementation of therapeutic changes, counselling on immunosuppression and biologic counselling as well as rapid review for unwell patients. This demonstrates the extensive skillset of the IBD CNS workforce and the aspiration of many CNS’s to provide a holistic service to IBD patients.

**MDT working**

92% of services have regular MDT meetings, however, the detail of how these are run varies. 50% of CNS services use the CNS to deliver on every aspect of the MDT from creating the patient list to collating patient data for discussion, documenting all outcomes, taking responsibility for ensuring the outcomes are carried out and relaying any changes back to the patient. This is labour intensive, time consuming and not recorded in any visible manner for the organisation. 66% of CNS’s take the minutes or complete the MDT proforma during the meeting and 66% of CNS’s are responsible for coordinating all of the outcomes from the meeting.
It could be argued that this is inappropriate use of the CNS skillset and could be more appropriately managed if this workload was spread across the MDT such as using admin staff and data managers to create patient lists, take minutes and record the outcomes. Shared responsibility with medical staff for co-ordinating the outcomes from the meeting could also be an effective way of ensuring a more even spread of workload.

These changes would also allow the CNS to be more actively involved in the MDT clinical decision making process with associated improvement in patient representation and advocacy.

**Biologics**

All CNS services co-ordinate and monitor the patients on biologic therapy. 86% of services use infusion nurses to administer the drug, but that is all they are responsible for. The CNS is responsible for co-ordinating all other aspects of the patient journey including patient counselling, work up screening, arranging administration, blood monitoring, review, co-ordinating reassessment and maintaining regular contact with the patient while they are on this therapy.

Only 43% of services have dedicated infusion units to administer the infusions, a further 36% use ambulatory day care areas and the remaining 21% use ad hoc areas such as inpatient wards or treatment rooms.

Starting and maintaining a patient on biologic therapy is a complex and labour intensive process requiring significant co-ordination. To date, this process has never been nationally mapped out and clear lines of responsibility within the MDT identified. Historically, this has fallen to the IBD CNS; however, with the significant rise in biologic use over recent years, current ways of working are unlikely to be sustainable.
Methodology

14 face to face interviews were carried out between 01.12.16 – 09.02.17 covering a total of 10 Health Boards. A structured questionnaire based on the recommendations illustrated above was used. Each interview took approximately 2hrs. Any additional data was added as free text at the end of the questionnaire.

The visit questionnaire was divided into 5 sections as identified by the National IBD Blueprint (2016), the RCN IBD Nurse audit (2012) and the author’s clinical experience as an IBD Nurse specialist. The sections were:

- Service
- Phoneline
- Clinic
- Multidisciplinary Team (MDT) working
- Biologics

This approach was taken as the writer was keen to get a real ‘feel’ for how the IBD services ran on a day to day basis. There was also a free text section where any other points of note or discussion were recorded.
Results

Service

Question 1: What is your title?

26 different titles were identified (Appendix 1).

Question 2: What title is on your Job description (JD)?

50% (n=7) CNS’s title on their ID badge is not the same as that on their job description.

Question 3: Do you have a job plan?

57% (n=8) CNS’s do not have a job plan

Question 4: When was your last appraisal?

92% (n=13) CNS have an annual appraisal. Free text responses to this question also revealed that this was the only formal time many CNS’s had with their managers. Only 14% (n=2) have regular contact with their manager in between appraisals.

‘...we should have monthly 121’s but they never happen’

‘I haven’t had a 121 for years’

‘121’s are difficult to arrange, they don’t happen’

‘We don’t have 121’s in-between our appraisals’
Question 5: Who manages you?

<table>
<thead>
<tr>
<th>Lead Nurse Acute Services</th>
<th>Other CNS</th>
</tr>
</thead>
<tbody>
<tr>
<td>78% (n=11)</td>
<td>22% (n=3)</td>
</tr>
</tbody>
</table>

This question generated a lot of discussion with the many CNS’s expressing some frustration at the general lack of understanding of the CNS role by Lead Nurses:

‘Any service changes require lots and lots of narrative before they can be carried out. No one understands the role’

‘I feel unsupported by management; they don’t understand what I do. I’m not given any guidance on service design or development. I just mop up all of the patients’

‘I have had 6 or 7 managers in the last 10 years. None of them take the time to understand what a CNS service looks like or what the service needs are. Their agenda and priorities are all about acute patient management. I manage a chronic caseload’

‘I want to audit my service, but I don’t know where to start’

Question 6: Do you have a dedicated role in IBD?

71% (n=10) CNS services are not dedicated to IBD. Other roles include hepatology, coeliac disease, haemochromatosis, rheumatology, endocrinology, metabolic disorders, endoscopy, nutrition and other non-IBD related gastrointestinal disorders.
Question 7: If no, how much time is formally dedicated to IBD within your JD?

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Time dedicated to IBD per service (WTE)</th>
<th>Number of nurses in post</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Ayrshire &amp; Arran</td>
<td>0.2</td>
<td>1</td>
</tr>
<tr>
<td>NHS Dumfries and Galloway</td>
<td>0.8</td>
<td>2</td>
</tr>
<tr>
<td>NHS Fife</td>
<td>Unobtainable</td>
<td>7</td>
</tr>
<tr>
<td>NHS Forth Valley</td>
<td>1.2 (Adults)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>0.2 (Paediatrics)</td>
<td>1</td>
</tr>
<tr>
<td>NHS Grampian</td>
<td>2.2 (Adults)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>0.6 (Paediatrics)</td>
<td>2</td>
</tr>
<tr>
<td>NHS GGC</td>
<td>3.5 (Adults) – GRI</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>1.3 (Adults) – Stobhill</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>2.5 (Paediatrics)</td>
<td>3</td>
</tr>
<tr>
<td>NHS Highlands</td>
<td>1.65</td>
<td>2</td>
</tr>
<tr>
<td>NHS Lanarkshire</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>NHS Lothian</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>NHS Tayside</td>
<td>2.1</td>
<td>3</td>
</tr>
</tbody>
</table>

Question 8: How many nurses are in this service?

<table>
<thead>
<tr>
<th>One</th>
<th>Two</th>
<th>Three</th>
<th>Four or more*</th>
</tr>
</thead>
<tbody>
<tr>
<td>7% (n=1)</td>
<td>43% (n=6)</td>
<td>36% (n=5)</td>
<td>14% (n=2)</td>
</tr>
</tbody>
</table>

* The maximum was 7 nurses in one service.
Question 9: How many consultants does the CNS service support?

<table>
<thead>
<tr>
<th></th>
<th>One (n=1)</th>
<th>Two (n=2)</th>
<th>Three (n=2)</th>
<th>Four or more* (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>7%</td>
<td>14%</td>
<td>14%</td>
<td>65%</td>
</tr>
</tbody>
</table>

*The maximum was 7 Consultants in 1 service. Of note, this was not the same service which had 7 IBD nurses in post.

Question 10: Do you have a formal IBD medical lead?

57% (n=8) services have a formally identified IBD medical lead. Some services identified Consultants with the highest IBD caseload, however this did not equate to a formal medical IBD Lead role.

Question 11: Population size?

0% (n=0) knew the population size for the Health Board area.

Question 12: Caseload size?

0% (n=0) of the CNS’s interviewed had robust figures on their caseload size.

Question 13: Do you have formal admin support?

<table>
<thead>
<tr>
<th>Dedicated for CNS</th>
<th>Shared with medical staff</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>29% (n=4)</td>
<td>64% (n=9)</td>
<td>7% (n=1)</td>
</tr>
</tbody>
</table>

Some services with shared admin support still had to carry out some admin tasks:

‘...letters get typed but we do not have a secretary on site so any scanning etc is done by us’ (Band 6 CNS’s)

‘we type our own letters because they wait too long’ (this service had shared admin support)
‘I type my own letters if they’re urgent’ (this service had shared admin support)

Question 14: Do you dictate letters?

86% (n=12) CNS services dictate letters. Of note, the 2 which did not dictate letters were paediatric services.

Question 15: Do you have an IBD patient database?

64% (n=9) CNS services had a database. 55% (n=5) of these services used the Biologics database, the remaining 45% (n=4) had their own service specific database.

Question 16: Who manages this?

Of those services with a database, 66% (n=6) were maintained and managed by the IBD CNS. This included inputting data. Only 1 service had admin support identified to do this.

**Phoneline**

Question 17: Do you run a telephone advice line?

100% (n = 14) answered yes

Question 18: Who picks up the calls?

The majority (78%; n = 11) IBD CNS’s pick up the calls themselves with only 22% (n = 3) using admin staff to do this.

Question 19: How often are the calls picked up?

64% (n = 9) CNS services pick up the calls in an ad hoc fashion throughout the day and 28% (n = 5) pick up calls at planned times during the day. Only 14% (n =2) of CNS services run telephone clinics.
Question 20: How do you triage/document the calls?

71% (n = 10) CNS services document the calls on paper with the remaining services documenting electronically either directly onto a patient management system or via email.

Question 21: How many calls do you receive per day?

On average CNS services receive between 33 – 39 calls to the advice line per week (range 15 – 100).

Question 22: How is the contact documented in the patent notes?

78% (n = 11) CNS Services document telephone contact electronically using a variety of methods. 21% (n = 3) still use paper notes. Not all telephone contact was documented.

<table>
<thead>
<tr>
<th>Electronic patent record</th>
<th>Electronic letter</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>42% (n=6)</td>
<td>21% (n=3)</td>
<td>14% (n=2)</td>
</tr>
</tbody>
</table>

Question 23: Do you run a telephone clinic?

Only 21% (n = 3) IBD CNS services run telephone clinics with all other services returning calls ad hoc throughout the day.

Question 24: Do you actively promote email communication with the patients?

Only 7% CNS services (n = 1) actively promote email communication with the patient group. This was a Paediatric CNS service. When asked about this, most adult CNS services said they did not think adults would ‘buy into’ this as a method of communication.
Clinic

Question 25: Do you run a nurse led clinic?

85% (n=12) of CNS’s interviewed run clinics. Of note, the 2 CNS services which did not run clinics were paediatric services.

Question 26: Is it nurse led or supported by medical staff?

66% (n=8) of nurse clinics are purely nurse led. The remaining services (34%; n=4) run parallel clinics with medical staff although the CNS carries out an autonomous review. 3 of the 4 parallel clinics are run under the name of the Consultant, not the CNS.

Question 27: How was it set up?

58% (n=7) CNS’s set up their own clinics including negotiating for clinic space and clinic frequency. 33% (n=4) were set up by CNS managers. The remaining nurse clinic was set up by the Gastroenterology consultant who also decided the frequency of nurse clinics for that service.

Question 28: Do you have a clinic proforma?

41% (n=5) CNS services have a clinic proforma and not all CNS’s have control over who books patients onto their clinic.

Question 29: How many face to face clinics do you run per week?

25% (n=3) services run daily clinics, 25% run twice weekly clinics and 25% run once weekly clinics. The remaining 25% run clinics 3 – 4 times per week.
Question 30: Are IBD patients seen in a dedicated IBD medical clinic?

<table>
<thead>
<tr>
<th>Dedicated</th>
<th>General GI</th>
</tr>
</thead>
<tbody>
<tr>
<td>50% (n=7)</td>
<td>50% (n=7)</td>
</tr>
</tbody>
</table>

Of those services who reported IBD patients being seen in general GI clinics, a further 28% (n=4) reported that the associated nurse led clinics were IBD specific.

Question 31: How long are the nurse led clinic slots?

100% (n=12) nurse led clinics run 20-30min slots.

Question 32: Do you offer formal rapid access?

64% (n=9) of services offer formal rapid access with clinic slots identified for this. The frequency of these clinic slots vary from weekly to daily. 36% (n=5) do not offer formal rapid access but the CNS will see the patients if necessary. This is ad hoc and not recorded formally. Patients are seen in Day Care areas, Inpatient areas or added to CNS clinics.

Question 33: What is your DNA rate?

25% (n=3) CNS services had data immediately available on this quoting an 8 – 10% DNA rate. 66% (n=8) did not have data but gave a verbal report that it was low. The remaining service did not know.

Question 34: Do you discuss patients seen at your clinic with the MDT formally?

25% (n=4) of services running nurse led clinics have formal clinical governance processes in place in the form of an MDT discussion. The remaining services approach the relevant consultant on an ad hoc basis.
**MDT**

Question 35: Do you have an identified IBD MDT?

92% (n=13) services have identified MDT personnel for IBD.

Question 36: Who is in your IBD MDT?

<table>
<thead>
<tr>
<th>Gastroenterologist</th>
<th>CNS</th>
<th>Surgeon</th>
<th>Radiologist</th>
<th>Pathologist</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% (n=13)</td>
<td>100%(n=13)</td>
<td>(n=6)</td>
<td>(n=4)</td>
<td>(n=4)</td>
<td>(n=11)</td>
</tr>
</tbody>
</table>

*Other MDT staff include junior medical staff, Registrars, dietitians and psychology. Of note, the psychologist was a member of the paediatric team.

Question 37: Do you have regular and planned MDT meetings?

92% (n=12) answered yes to this. Meeting time ranged from 30 mins – 2hrs.

Question 38: If yes – how often?

91% (n=11) had weekly meetings. The remaining 8% (n=1) met monthly.

Question 39: Who ATTENDS these MDT meetings?

<table>
<thead>
<tr>
<th>Gastroenterologist</th>
<th>CNS</th>
<th>Surgeon</th>
<th>Radiologist</th>
<th>Pathologist</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td>83% (n=10)</td>
<td>83% (n=10)</td>
<td>58% (n=7)</td>
<td>50% (n=6)</td>
<td>50% (n=6)</td>
<td>50% (n=6)</td>
</tr>
</tbody>
</table>
*Other MDT members were dietitians, junior medical staff, Registrars, research fellows, pharmacy and psychology. Of note, the psychologist was a member of a paediatric team.

Question 40: What is the meeting format?

50% (n=6) services use a member of admin staff to generate a patient list. 33% (n=4) use the IBD nurse to generate the list and the remaining 2 services use junior medical staff to generate the list.

Question 41: Who co-ordinates the MDT meeting?

50% (n=6) CNS services co-ordinate the MDT. The full process of co-ordination by admin staff is carried out by only 33% (n=4) services.

Question 42: Are minutes taken?

92% (n=11) for MDT meetings had some form of minutes taken.

Question 43: If yes – by whom?

66% (n=8) CNS’s either take minutes or complete an MDT proforma. Admin staff are used to take minutes in only 17% of services (n=2).

<table>
<thead>
<tr>
<th>CNS</th>
<th>Admin</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td>66% (n=8)</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>66% (n=8)</td>
<td>17%</td>
<td>17%</td>
</tr>
</tbody>
</table>

*Other members of the MDT who took minutes were junior medical staff.

Question 44: Who presents the patients at the MDT meeting?

Only 50% (n=6) of CNS’s present the patient at the MDT.
Question 45: Who co-ordinates the meeting outcomes?

66% (n=8) of CNS services have responsibility for ensuring that outcomes generated from the meeting are followed through. 17% (n=2) are informed of any nurse specific outcomes via letter dictated at the meeting by medical staff.

**Biologics**

Question 46: Are you involved in the decision process to start a patient on a biologic?

57% (n=8) IBD teams do not involve the CNS in the decision making process to start biologic therapy. The remaining 43% (n=6) make an MDT decision.

Question 47: Do you personally administer biologic infusions?

86% (n=12) CNS’s do not administer biologic infusions.

Question 48: Do you have an infusion unit?

<table>
<thead>
<tr>
<th>Dedicated infusion unit</th>
<th>Ambulatory day care area</th>
<th>Inpatient area</th>
</tr>
</thead>
<tbody>
<tr>
<td>43% (n=6)</td>
<td>36% (n=5)</td>
<td>21% (n=3)</td>
</tr>
</tbody>
</table>

Question 49: Do you have infusion nurses?

86% (n=12) services have infusion nurses (nurses who are responsible for administering the infusions only).
Question 50: How often do you (the CNS) review biologic patients?

<table>
<thead>
<tr>
<th></th>
<th>Every infusion</th>
<th>3 Monthly</th>
<th>At clinic</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>28% (n=4)</td>
<td>21% (n=3)</td>
<td>28% (n=4)</td>
<td>21% (n=3)</td>
<td></td>
</tr>
</tbody>
</table>

Question 51: Do you carry out autonomous clinical reviews for biologic patients?

86% (n=12) CNS services carry out autonomous clinical reviews on biologics patients.

Question 52: How do you monitor bloods for patients on biologics?

<table>
<thead>
<tr>
<th>CNS</th>
<th>*GP</th>
<th>**Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>43% (n=6)</td>
<td>50% (n=7)</td>
<td>7% (n=1)</td>
</tr>
</tbody>
</table>

*Not all GP services routinely monitor patients on biologic therapy. Some will only monitor if the patient is also using a background medical therapy (eg: Azathioprine or Methotrexate)

** Medical staff monitor bloods

Question 53: Any other comments about managing patients on biologics?

This generated a lot of comments, mainly focussed on the workload generated for the CNS:

‘Homecare nurses do the Humira loading at home, they have pathways for the blood monitoring too. That has freed time for us to develop the service.’

‘Pre-infusion bloods are very ad hoc – these patients are usually rammed into an (overbooked) clinic. Most of our workload is managing biologic patients’

‘Why are we checking pre-Infliximab bloods? How much does it cost? Is it a real risk?’

‘We don’t deliver the infusions but we co-ordinate every other aspect of the process’ (this area has a specific infusion suite).

‘Biologics are very time consuming – the process is labour intensive’
“We have so many patients on biologics now, it’s really difficult to keep track of them all.”

**Nurse qualifications**

Question 54: Are you a non medical prescriber?

64% (n=9) do not have a non-medical prescribing qualification.

Question 55: Do you have an advanced patient assessment qualification?

71% (n=10) do not have an advanced patient assessment qualification.

Question 56: Do you have an IBD specific qualification?

43% (n=6) have a specific IBD related qualification. 83% (n=5) of these did the qualification more than 9yrs ago.

The final element of the questionnaire was a statement asking the CNS to identify one positive and one negative aspect of their service. All responses have been reported.

State one positive aspect of your service:

72% (n=10) responded with a very clear patient focus:

‘Patients love it’ (x2)

‘Patients get good quality care’

‘Patient response to us is good – they tell us the service is invaluable’

‘IBD patients have an excellent service. The majority of calls are answered daily or we can see them that day.’

‘We have lots of patient contact’

‘The patients have great access now’
‘The patients get a tight service with a good process for managing the calls’

The remaining 28\% (n=4) had a more service focussed response:

‘Setting up clinics has allowed us to look at the bigger picture because now things are more organised. We can manage things more proactively now’.

‘Our new manager has been a huge positive change because we feel understood and supported. She is showing us service design changes.’

‘We’ve (the nurses) invested a significant amount of time organising our MDT – that’s allowed the coming together or decent people with the same objective’

‘The Transforming OPD project gave us buy in from the managers and helped us form the (nursing) service into something tangible and measureable’.

State one negative aspect of your service:

50\% (n=7) had MDT related responses:

‘Not enough dedicated and supported time with the MDT’

‘The medical hierarchy still exists’

‘No MDT cohesion – it’s still them and us’

‘I’m under supported by medical staff’

‘We need more dedicated time for MDT’s. We’re still not viewed as an equal.’

‘Need more formalised contact time with medical staff.’

‘The MDT isn’t working – there’s no cohesion. It’s just about giving instructions – there’s no respect for us a CNS’s.’

50\% (n=7) had resource related responses:

‘Currently our medical staff shortage is an issue’

‘I don’t have enough resource to deliver on patient contact’
‘We need more nurses to allow me time to design a better quality and more organised service.’

‘More resource needed to increase efficiency’

‘We need a data manager – don’t know our caseload size’

‘Work is hard to prove’

‘Data management is vital but lacking – we can’t prove our worth if we don’t have the data.’
Discussion and recommendations

CNS Services

71% of CNS’s in post as an IBD CNS are not dedicated to IBD. Other roles include: hepatology, nutrition, endoscopy, coeliac disease, IBS, endocrinology, rheumatology and metabolic disorders (this list is not exhaustive). The specific number of hours allocated to IBD for many services was not clearly defined in the job description therefore contracted hours in IBD were not specified in many cases due to the variability in roles covered by each CNS service. The National Standard for IBD CNS’s in post is 1.5 WTE per 250,000 (IBD Standards 2013). Given that 71% of CNS’s have other roles, it makes it highly unlikely that we are meeting this standard. More recent (as yet unpublished) work carried out by Crohn’s and Colitis UK is demonstrating a more realistic number of 2.5 WTE per 250,000 with a maximum caseload of 500 patient per CNS (Crohn’s and Colitis UK 2017). This work has also demonstrated that many nurses are involved in pre-diagnostic work. This was not addressed within this report specifically; however it is nationally emerging data which also has an effect on the CNS workload. Job descriptions are not standardised – even within the same Health Board.

Endoscopy sessions were clearly defined, however not all endoscopy patients were IBD patients so this did not provide any further clarity in terms of clearly identifying the IBD patient load.

Furthermore, there is no parity in post titles, with a total of 26 different CNS titles identified. In some cases local organisational infrastructure dictated the CNS title which was not always clear. An example of this is the paediatric service in NHS Forth Valley where the GI specialist nurse is called a Community Children’s Nurse (with a specialist interest). The corporate identification of this service is therefore under Community Children’s Nursing which makes the specialist nature of the role unclear and invisible. This principle is also evident across other Health Boards where a generic title is in place although the CNS carries out many specialist (and unseen) roles.

78% of services are managed by Lead Nurses who have additional management responsibilities and priorities – namely acute service management. IBD CNS’s manage a chronic patient caseload which has very different patient and service requirements than managing acute services. Clinical autonomy and service development are 2 areas in particular which are fundamental to the CNS role (Leary and Oliver 2010) and many CNS’s report a general lack of understanding of the complexity of the role by their nurse managers. This is demonstrable by some of the additional comments from the CNS’s interviewed:

REF NO. HS/S5/18/HCSS/42
'Any service changes require lots and lots of narrative before they can be carried out. No one understands the role'

'I have had 6 or 7 managers in the last 10 years. None of them take the time to understand what a CNS service looks like or what the service needs are. Their agenda and priorities are all about acute patient management. I manage a chronic caseload'

57% of CNS's have no job plan and although 92% have an annual appraisal, very few have any clinical mentorship or guidance from Lead Nurses in between. The lack of appropriate clinical leadership is likely to have influenced the development of the heterogeneous CNS services demonstrated. This report reveals that many IBD CNS’s in post already demonstrate clear leadership skills and this is evident through many of the service development initiatives already seen (NHS Tayside telephone clinics, NHS Highland MDT co-ordination, NHS GGC email clinics etc..). Strategic leadership is vital if services are to develop in an efficient way (National Clinical Strategy 2016). Harnessing the already existing clinical and managerial expertise within the IBD CNS workforce may be a more effective way of ensuring that IBD CNS services continue to develop efficiently. This would also have the added value of delivering on the 2020 Workforce Vision which advocates ‘valuing and developing management skills and having managers who lead by example’ (Scottish Government 2013).

Furthermore, the development of a standardised and nationally agreed IBD CNS job description for junior and senior IBD nurses would help address the current heterogeneity in the role. This ‘core’ job description could then provide a standardised framework on which each organisation could build according to individual service needs and local infrastructure. This framework already exists as a consensus guideline produced by European Crohn’s and Colitis Organisation (ECCO) (O’Connor et al 2013) and is one of the key recommendations of the National IBD Blueprint 2016.

Finally, of note is the activity of the RCN Gastro forum, RCN National IBD Nurse Network and the newly re-formed Scottish IBD Nurse Network. These are forums which have been set up and continue to function purely on the input from CNS’s (often in their own time). They are vital for the continued supervision, development and support of IBD CNS’s and a further demonstration of the knowledge and expertise available within this field of nursing.
Caseload and data management

None of the CNS’s interviewed had robust data on the size of their caseload. The specific reasons for this may be beyond the scope of this report; however information sent to the Information Services Division (ISD) may have some bearing on this. Only 1 CNS service sent data to ISD. This data is coded to the CNS specifically. No other services were asked for this information, in fact one service reported they had asked for CNS specific ISD codes but were told they did not exist and CNS’s had to be coded to Consultant ISD codes. Given that 34% of CNS nurse led clinics are coded under the Gastroenterologists name, this further exacerbates the problem of accurately quantifying the CNS clinical workload. All IBD patients do not require IBD CNS input, so coding against IBD as a diagnosis or a specific Gastroenterologist will not give robust data on CNS activity. Planning for service delivery and development is not possible without this data.

66% of CNS services with a database use the IBD CNS to manage and maintain this. This is inappropriate use of the CNS skillset and time. A standardised framework for CNS services including the use of admin and data management support may address this and allow the CNS skillset to be used more appropriately and for the direct benefit of the patient. This report has demonstrated a void in robust data such as exact caseload size for IBD CNS’s which makes planning for services very difficult. Employing data managers would be a more cost effective and robust way of gathering this vital data.

This is also the case for admin support. Although this appears to be improving from the RCN 2012 data (16% ‘v’ 64%), on closer examination, only 29% of CNS services have dedicated admin support and those with shared support are still carrying out admin tasks. Planning for all new CNS posts INCLUDING admin cover would free up CNS time put their skill set to more appropriate use such as service design, patient education and delivery of expert clinical care where necessary.

The ‘Leading Better Care’ document (2008) carried out a review of senior charge nurses (SCN) and provided a framework in which they could develop their role based on specific and measureable clinical quality indicators (CQI’s). While there are particular aspects of the CNS role which differ from an SCN (specifically, degree of clinical autonomy and chronicity of caseload), the principles applied in the ‘Leading Better care’ document could be applied to the IBD CNS group to provide a framework on which to base a more accurate assessment of the CNS workload. The author is aware that Crohn’s and Colitis UK are currently working on developing a tool to accurately measure the IBD CNS workload – this should be able to provide vital information for future service design and development.
Medical staffing

There is no parity in the number of medical staff in post and the number of CNS staff in post to support the medical role. An example of this is NHS FV where there are 2 IBD CNS’s and 7 consultant Gastroenterologists carrying an IBD caseload. Although specific IBD leads are identified, new patients are not automatically transferred to them if diagnosed by another consultant. This leaves the IBD CNS ‘chasing’ several consultants and makes standardisation and consensus almost impossible. Although this Health Board has the lowest ratio of CNS’s to Gastroenterologists, the phenomenon of IBD patients being carried by several consultants is across all Health Boards. Only 57% of services had a formally identified medical lead for IBD. This makes the day to day running of associated CNS services much more challenging as medical staff availability is often in short supply resulting in protracted decision making. Identification of a dedicated and functional IBD MDT would help address this issue to some degree, however, the dilution of the IBD caseload among several gastroenterologists further exacerbates the issue of defining an accurate caseload. Nationally agreed clinical pathways would help reduce this heterogeneity in practice and patient management – the National Blueprint (2016) will go some way towards this outcome.

Educational preparation

83% of those with and IBD specific qualification completed their programme more than 9yrs ago and have done nothing since. 71% do not have an advanced patient assessment qualification and 64% are not prescribers. Continuing professional development and lifelong learning are the cornerstones of advanced nursing practice (Scottish Government 2010, RCN 2012). ‘Workforce 2020’ (Scottish Government, 2013) specifically advocates that ‘everyone has time for learning and is supported to develop their skills, knowledge and competence’. Ensuring time for accessing appropriate educational opportunities requires clear nursing leadership, guidance and support. This is not available for many CNS’s. Of note, the Crohn’s and Colitis UK campaign ‘More Nurses = Better Care’ has set a standard for 95% of supporters to have access to a suitably qualified IBD CNS.

Currently no ‘core standard’ exists for IBD Nursing services including defining appropriate academic preparation for an IBD CNS. This is something which is currently being addressed by the Scottish IBD Nurse network and more broadly across the UK in the RCN IBD Nurse network.
Telephone advice lines

Although all CNS services run a telephone advice line, there is no standard process for this. 78% of services use the CNS to pick up the calls. This is not efficient use of Band 6, 7 or 8 time and could be delegated to admin staff. There are successful examples of this already in existence where the process is efficient and, most importantly, measureable (NHS Fife, NHS Tayside, NHS GGC).

Furthermore, 64% of CNS services pick the calls up ad hoc throughout the day with no dedicated time to triage, deal with and subsequently document the outcome. The time taken to deal with the call and the events generated by it is often not recorded in any robust way. Many nurses pick the calls up between other duties (clinics, endoscopy lists, inpatient reviews) with no clearly defined time in their working week to formally ‘run’ the telephone advice line. Access to patient advice via telephone and email is the first key recommendation in the National Blueprint (2016) and is fundamental to managing an IBD nursing service (IBD Standards 2013, RCN Audit 2012).

Documentation is clearly necessary both from a patient safety perspective and as a means of measuring workload. In some cases the documentation process involved writing an email and then asking secretarial staff to print, scan and upload the email onto the patient file. IT systems which ‘speak’ to each other could reduce this convoluted and labour intensive process and facilitate more efficient cross boundary communication (between Primary and Secondary care). Many GP’s do not have a GP email address – this further protracts communications as the patient has to wait until the letter is typed for any medication changes.

Furthermore, not all telephone contact is documented in the patient notes with many CNS services only documenting specific outcomes such as medication changes. This means other calls such as those relating to self management, lifestyle choices and other aspects of vigilance and rescue work go unrecorded. This type of work is fundamental to managing patients with chronic disease and is therefore vital to the CNS role (Leary & Oliver 2010). The National Clinical strategy (2016) highlights the need for proactively managing patients with complex health needs and reducing the need for admission to secondary care. Vigilance work, expert advice and patient education is therefore central to this ethos and a vital element of the CNS service. Heterogeneity in the process for managing telephone advice lines means that much of this vital workload is unaccounted for.

Excellent practice already exists with some CNS services documenting all calls on an electronic patient management system (PMS). Although this is not ideal as the CNS is still booking the patients onto the system (a task that could be done by a member of admin staff), it is an example of good practice in terms of capturing the data electronically.
This is a process which could be relatively easily rolled out across Scotland as most Health Boards have an electronic (PMS). Time to run the advice line should be clearly identified and ring-fenced within the CNS clinical hours and job plan. This is currently not the case and a significant proportion of this workload remains invisible. Telephone help lines have been shown to be largely cost effective (Squires et al 2015), however, implementing a standard framework for what this should ‘look like’ may add to these cost savings. The RCN have also published guidance on this (RCN 2012); of note, having the appropriate service infrastructure to support the telephone service is one of the recommendations in this document.

Finally, email is not used in the adult setting as a means of patient management. One service in GGC (paediatrics) has successfully implemented an email clinic which allows rapid access to expert advice in a more measureable way. Email clinics are run every afternoon allowing the CNS service to run in a more proactive manner. Although not yet formally audited for patient satisfaction, this has been presented at a European conference in 2017 (Garrick et al 2017) and anecdotal responses from parents report the benefit of much more flexibility in contacting the service. They are not interrupted at work to take a phone call and they also value having the response in writing to refer to. Investment in developing ehealth is vital in the changing landscape of the NHS (National Clinical Strategy 2016) and this is another immediately workable solution for CNS services with an appropriate service infrastructure to support this type of practice. Specifically, this involves the ring-fencing of dedicated time.

The Scottish IBD Nurse Network has identified telephone advice lines as a specific workstream and will be investigating the design and implementation of a more standardised approach to how these are run and measured. The aim of this piece of work is to produce some practical and evidence based guidance on how an IBD Telephone advice line can be run effectively.

Clinics

85% of the CNS services interviewed run nurse led clinics, 34% of these run parallel to medical clinics where CNS activity is coded to the medical consultant. This means that the list of patients seen by the CNS is coded to the medical consultant, not the CNS, resulting in an ‘invisible’ CNS workload despite an equivalent number of patients being seen in clinic. Many CNS’s have developed innovative ways of using their clinic slots so that fundamental elements of chronic disease management can be carried out.
Examples of this are in NHS Lanarkshire where specific slots are set aside to counsel patients starting biologic therapy. The logistical arrangements (blood work up, monitoring, arranging drug administration) can also be agreed during this time therefore the whole process is more efficient. NHS GGC (Glasgow Royal Infirmary) and NHS Tayside run nurse-led ‘biologic clinics’ where all patients on biologic therapy have a nurse-led review. Again, this is an example of innovative practice which could be shared and potentially used by other Health Boards. Further examples of this is NHS Ayrshire and Arran where the CNS has set up a ‘drug counselling’ clinic once weekly for all patients changing therapy (not only for biologic therapy). These are models which could be adapted and applied across various Health Boards.

Clinic frequency is disparate with some services running daily clinics while others run them weekly. Reasons for this are not clear, mainly because caseload size is not definable so it is not possible to correlate caseload with clinic frequency. Of note however is the fact that several nurses made comment on the fact that patients were never discharged. An ageing population and the subsequent pressure this will place on IBD services may mean that this may not be sustainable. The National Clinical Strategy (2016) recognises this and specifically identifies the need to support self management through empowering the patient to understand and subsequently manage their long term condition more effectively. In addition, the strategy recognises the importance of therapeutic rapport in the delivery of person centred care. CNS clinics are vital to the delivery of this.

64% of CNS services offer formal rapid access and review, although this is not always recorded robustly and not all rapid reviews are nurse-led. The unpredictable nature of IBD means that rapid review is necessary (Mowat et al 2011) and both the IBD Standards (2013) and National Blueprint (2016) advocate this as a quality indicator. Currently, there is no equitable process across each Health Board to ensure that this is incorporated into CNS service design. Indeed, there does not appear to be a standardised process for the use of nurse clinic slots as a whole and CNS’s described examples of under use (where the CNS is not ‘permitted’ to carry out rapid review for patients with increasing symptoms) and overuse (where patients are booked directly onto the CNS clinics from medical clinics for nurse follow up – this then leads to nurse-led clinics being fully booked with some ‘next available’ slots more that 12 weeks away). The automatic process is to rebook when this may not be necessary. Patients who are well could be discharged on an appropriate self management programme with annual IBD CNS input.
Applying a more structured approach to the design and implementation of nurse-led clinics has the potential to increase efficiency through using the CNS skillset more appropriately (e.g., for rapid review and expedited start of treatment at relapse as well as chronic disease management, disease education, monitoring, and proactive self-management) (Jorgensen et al. 2012).

75% of CNS services running nurse-led clinics do not have any formal process for clinical governance or peer review in complex patient management. Contact with the relevant consultant is done on an ad hoc basis which is both inefficient and carries some clinical risk. Ensuring clinical governance is fundamental to advanced nursing practice and a fundamental aspect of nursing (Scottish Government, Advanced Nursing Practice, 2010; NMC 2016). Formalising this process (for example through feedback of complex patients at the MDT meeting) would facilitate more robust clinical governance and allow for a smoother communication flow with the additional benefit of improving MDT communication.

**MDT**

92% of CNS’s interviewed reported having regular MDT meetings, however the specifics of how they are organised is variable with length of meeting ranging from 30 minutes to 2 hours and the method in which they are carried out heterogeneous. MDT working is one of the key recommendations in the National Blueprint (2016) and the positive impact on patient outcomes is well documented (Lamb et al. 2011, MacCallam and Higgins 2014). Some areas demonstrated very robust MDT meeting processes where each item was minuted, outcomes documented and responsibilities clearly outlined. Examples of this include NHS Highland where the MDT meeting process was re-vamped and is now more robust in terms of producing more measurable outcomes. Of note, the CNS service itself was responsible for this overhaul and is also responsible for most aspects of the process including creating the patient list, collating all of the clinical data and co-ordinating the meeting outcomes.

On the whole, CNS involvement in MDT’s was variable and ranged from having responsibility for all aspects of the meeting to having minimal input (meaning that the CNS attended the meeting but did not participate). 50% of CNS services co-ordinate every aspect of the MDT meeting from booking the room and creating the patient list to having responsibility for co-ordinating all of the outcomes. Paradoxically, only 50% of the CNS’s present the patient at the MDT, even if they have put the patient onto the list for discussion.
Their expert clinical knowledge, in addition to the often long established relationships the CNS has with many IBD patients, makes them perfectly placed to represent the patient both in terms of clinical decision making and from an advocacy perspective (O’Connor et al, 2013). Exploring the reasons for this are again outwith the scope of this document however, of note is the fact that many nurses describe issues around MDT functioning as a negative aspect of their service:

‘Not enough dedicated and supported time with the MDT’

‘No MDT cohesion – it’s still them and us’

‘Need more formalised contact time with medical staff.’

‘The MDT isn’t working – there’s no cohesion. It’s just about giving instructions – there’s no respect for us a CNS’s.’

MDT meeting design is also disparate with some teams allowing 2 hours while others allow as little as 30 minutes before a busy clinic starts. Time pressure is one of the many factors reported as having a negative effect on MDT working, excessive caseload another (Lamb et al 2011). Many CNS’s reported that they felt the MDT meeting was rushed with examples of CNS time being ‘added’ to the end of a much larger meeting (including junior medical staff education) so this was often a rushed process. Another common theme in reporting was the additional (and unrecorded) workload generated by managing the MDT outcomes. This was apparent across every service interviewed.

66% of CNS’s took minutes or completed the MDT proforma at the meeting with only 17% of services using admin staff to do this. Some services used admin staff to create the patient list for discussion, but the input ended there. 66% of CNS’s also had responsibility for co-ordinating the outcomes generated by the meeting. From experience, the author is aware that as many as 30 patients can be discussed at these meetings so a significant workload is generated and much of this is not currently measureable. Electronic patient management systems (ie: Trak) could be used to capture this data in terms of patient numbers discussed but admin support would be necessary to facilitate data entry and outcomes generated by the MDT. Furthermore, it could be argued that the workload generated from these meetings could be more evenly distributed across the MDT allowing the CNS skillset to be put to more appropriate use such as vigilance and rescue work or continued service development.
Providing a standardised framework for how an MDT should ‘look’ could start to address some of these inconsistencies. A standardised and agreed model which helped identify clear roles and responsibilities within the IBD MDT could help direct clinical staff to run these meetings more efficiently and spread the workload more evenly. Again, exemplars of practice in this area already exist. NHS Grampian (Paediatrics) have a ‘GI Service’ component to their meeting process which identifies who is available for the rest of the week and the various clinics which are running as well as who is covering inpatients, outpatients and clinics. This is done at the start of the meeting and takes about 5 minutes, however, the result is that all members of the team are then aware of each other’s clinical availability and communication is more cohesive. This would be particularly helpful for services which run clinics offsite (many CNS services cover more than one hospital). Again, this exact model may not be transferable across all services; however, including service issues as a general principle may be appropriate for some services. Other exemplars of MDT working have involved using GI pharmacists to more appropriately manage medicines in IBD. This has been particularly successful in NHS Lothian (Western General) where involvement with the pharmacist has freed up CNS time to deliver on more nurse specific roles such as designing group counselling sessions on biologics.

The Scottish IBD Nurse Network has identified MDT working as a specific workstream and will be investigating MDT functioning with a particular focus on CNS input. The aim of this piece of work is to produce some practical and evidence based guidance on how an IBD MDT can be run effectively.
Biologics

Although 86% of IBD CNS’s do not personally administer biologic infusions, only 43% of services have a dedicated infusion unit. The remaining services use ambulatory day care areas or inpatient areas. Infusion nurses were identified in 86% of services, however, these nurses are only responsible for the administration of biologic therapy. All other aspects are co-ordinated by the CNS teams and the workload generated by this was commented on:

‘...most of our workload is managing biologic patients’

‘We don’t deliver the infusions but we co-ordinate every other aspect of the process’

‘Biologics are very time consuming – the process is labour intensive’

‘We have so many patients on biologics now; it’s really difficult to keep track of them all’.

Of note, NHS Lanarkshire has recently appointed a ‘Biologic Nurse’ whose role is to manage all patients on biologic therapy. This is not a GI specific role however, it also encompasses patients from Rheumatology and Dermatology specialties. This service was also the only one which did not co-ordinate every aspect of the patient journey onto biologic therapy. Junior medical staff co-ordinate and subsequently interpret pre-screening bloods although the CNS is still responsible for all drug counselling with this patient group.

More than half (57%) of IBD services in Scotland do not include the IBD CNS in the decision to start a biologic therapy. While the ultimate responsibility will always be with medical staff, the principles of peer review and an MDT approach to patient management would support inclusion of the CNS in this process. CNS services are almost solely responsible for the management of these patients including counselling, co-ordinating treatment work up, co-ordinating and carrying out monitoring and arranging treatment (either in hospital or at home). It makes sense therefore they are involved in the process from the outset as their therapeutic relationship with the patient is vital when communicating about biologic therapy (Danese et al 2017). This would also have the added benefit of all team members being aware of timelines for starting, monitoring and reassessing these patients. Exemplars of practice include NHS GGC where virtual biologic clinics are held with an MDT review and clear outcomes from each meeting to ensure the patient and response to therapy is monitored effectively.
Patient monitoring is variable with 43% of services using the CNS for this while 50% of services use the GP. This is however not as straightforward as it sounds with many GP’s only monitoring patients on injectable biologic therapy or if they are using Azathioprine or Methotrexate as combined therapy. The reason for this is unclear and arguably illogical as the same bloods are monitored and parameters used for both biologic and background therapies. A further example of variability in practice is CNS involvement in arranging and monitoring pre-screening bloods for intravenous biologic therapy. This creates a significant workload for the CNS in terms of identification of patients and co-ordination of samples taken one week before the infusion, subsequent checking, contacting the patients and arranging the infusion. This report identified 2 areas where pre-screening bloods were not done (NHS Highland and NHS GGC) with no adverse events recorded. The author has also asked about this practice through the UK wide IBD Nurse network and there appears to be little evidence to suggest that this is a necessary process. A full clinical assessment is done before every intravenous biologic infusion given in hospital, however, this is not done by a qualified clinician before every dose of injectable biologic therapy given by the patient at home. Neither do these patients have bloods monitored before every injection.

This appears to be a historical process which may benefit from review due to the labour intensive nature of the process. A significant amount of time is spent by CNS’s tracking, monitoring, interpreting results and subsequently communicating with the patient before their infusion. This merits further investigation as cost savings could be made in terms of the cost of phlebotomy, CNS time and patient time out of work to attend for a potentially unnecessary appointment. It may be that evidence is not available to discontinue this practice completely, however, a standardised and agreed approach to the process is likely to be more efficient in terms of time for both the patient and clinicians managing them. Much of the process for this is admin related so could be delegated to admin staff if mapped out appropriately.

There is also no parity over the process for frequency of review with 28% of CNS’s reviewing patients at every infusion and 21% not reviewing the patient at all (the patient is reviewed routinely at clinic). The reality of medical clinic slots is that they are often full for months at a time which means the ‘first available’ slot may be outwith an acceptable window for review. NHS Tayside are looking at creating a local pathway to help address the current clinician specific approach to this – another example of innovative practice which may be appropriate for other Health Board areas with a suitable infrastructure to support this. As previously identified, some CNS services have as many as 7 members of medical staff for whom they co-ordinate patient care.
Clearly, if all clinicians do not manage this in the same way, the CNS workload generated is significant. Standardising a nationally agreed biologic monitoring pathway including agreed timing for therapeutic drug monitoring and involving Primary Care, would be a potentially effective way of freeing up CNS time as well as supporting the framework suggested by the National Clinical Strategy (2016) in terms of removing the focus from secondary care provision.

Further examples of efficient practice is demonstrated by NHS Lothian who have initiated the use of an external agency (Homecare services) to administer loading doses of Humira at home, thus reducing the need for a hospital visit for the patient and also facilitating care close to home (Better Health, Better Care 2008). Again this is a process which could be rolled out across Scotland if the appropriate infrastructure was in place to support it. Many hospitals already use Homecare agencies for the delivery of other injectable therapies and many have nurse support written into their Standard Operating Procedures. NHS Lothian have also benefited from using a pharmacist with a specific interest and knowledge base in IBD to help rationalise biologic medicine management and provide a process for managing patients on biologic therapies. This is an excellent example of MDT working which has the added benefit of releasing CNS time to focus on more nurse related issues such as patient self management, clinics for annual review, counselling or service development.

There are also areas where CNS’s with a non-medical prescribing qualification still do not prescribe biologic therapies. It could be argued that this is under utilisation of the CNS skillset while also adding an additional link in an already complex chain of events to initiate biologic therapies. In these cases the IBD nurse has to find a member of medical staff to prescribe the biologic therapy which is both time consuming and unnecessary. Providing a ‘Biologic Patient Framework’ which maps out the patient journey on biologic therapy may help address some of these inconsistencies in practice.
Recommendations

CNS service design and structure:

- Clear specialist nursing leadership is lacking. There are senior specialist nurses already in post who could lead on IBD CNS service development and delivery with some service re-design.

- The IBD CNS role is still not clearly defined. Standardised and nationally agreed IBD CNS job descriptions for junior and senior levels of specialism is necessary.

- Clear and defined admin support is lacking. Particular input into telephone advice lines, MDT meetings and Biologic patient management would free up CNS time to use the skillset more appropriately.

- Data managers are needed to more efficiently manage databases and provide robust data on CNS workload and caseload size.

- The CNS workload is currently invisible at health Board and National level. ISD coding specific to CNS’s would address this.

CNS service specifics:

A definitive and standardised nurse led clinic framework using some of the many innovative examples of nurse led expert practice seen in this review would be helpful in addressing this. These could be adapted locally to suit the organisational infrastructure and would include clear clinic proformas and governance processes. Examples include:

- Biologic clinics
- Group counselling sessions for patients starting similar biologics
- Telephone clinics for review
- Nurse run email clinics
Limitations

The CNS questionnaire was not run as a pilot due to the limited timeframe. If this process were to be repeated, this would be recommended to prove validity and reliability of the tool.

Interviews were not transcribed verbatim. This may have resulted in some information not being recorded although the author made every effort to document all salient components of the conversation.

Although most Health Boards with an IBD CNS were represented, not all CNS services within each Health Board have been represented within this report. Some Health Boards cover more than one hospital so will have more than one CNS service in their remit. This is most applicable to GGC which covers 8 hospitals but only 3 CNS services were interviewed.
Conclusion

Despite the RCN Role descriptives (2007), RCN IBD nurse audit (2012) and the IBD Standards (2013), disparity remains in IBD CNS services across Scotland. Even within the same Health Board, job descriptions are not standardised nor a set of core standards available identifying the basics of setting up an IBD CNS service. The result of this is that although on the surface many services appear to have some parity in terms of running telephone advice lines, MDT meetings and managing Biologic patients, there remains significant heterogeneity in the detail of how these services are run day to day.

Historically many CNS roles have developed as a result of medical staff recognising the need for CNS input and subsequently requesting this from nursing management. Unfortunately, this may be to the detriment of the CNS role as this report has demonstrated that many Lead Nurses do not have an in depth understanding of what the role requires, resulting in the creation of hybrid CNS roles. Only 29% of services have a CNS with an IBD specific role and even fewer with an IBD specific role working full time hours.

Continuity is essential in the management of chronic disease (O’Connor et al 2013) both from a patient perspective and an economical perspective. The IBD CNS is perfectly placed to address this with positive outcomes for both the patient and finance but more dedicated time will have to be allocated with fewer hybrid roles developed to fill these spaces.

The National Blueprint (2016) specifically highlights ‘maximising workforce efficiency and productivity’ as one of the primary drivers for the programme. This report has demonstrated that the IBD CNS workforce in Scotland is currently not being used to its full advantage. Much of the clinical workload is unrecorded at a national level thus making this vital element of specialist nursing invisible. Fundamental elements of chronic disease management (vigilance calls, rescue work, self management teaching, disease education, managing lifestyle issues) often go unrecorded. The CNS skill set is diluted with tasks which could be delegated to less clinically skilled members of the MDT such as admin staff or data managers.
This report has demonstrated some of the innovative practice already in place in some Health Boards. However, currently many CNS services are working in silo’s (even within the same Health Board) meaning that this practice is not shared. The Scottish IBD Nurse Network is making significant inroads into addressing this, however these improvements in communication must also be considered at national policy level if they are to have any impact on the delivery of IBD CNS services.

Finally, clear nursing leadership is lacking. Clinical nurse leaders already exist in this workforce as has been evidenced by the innovative practice demonstrated at the start of this report. Harnessing this leadership to provide a CNS framework on which to accurately measure, assess and evaluate workload would ensure the provision of robust data and a more standardised approach to IBD CNS service design and development.
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Appendices

Appendix 1: Demographic data of IBD CNS services

Appendix 2: Questionnaire