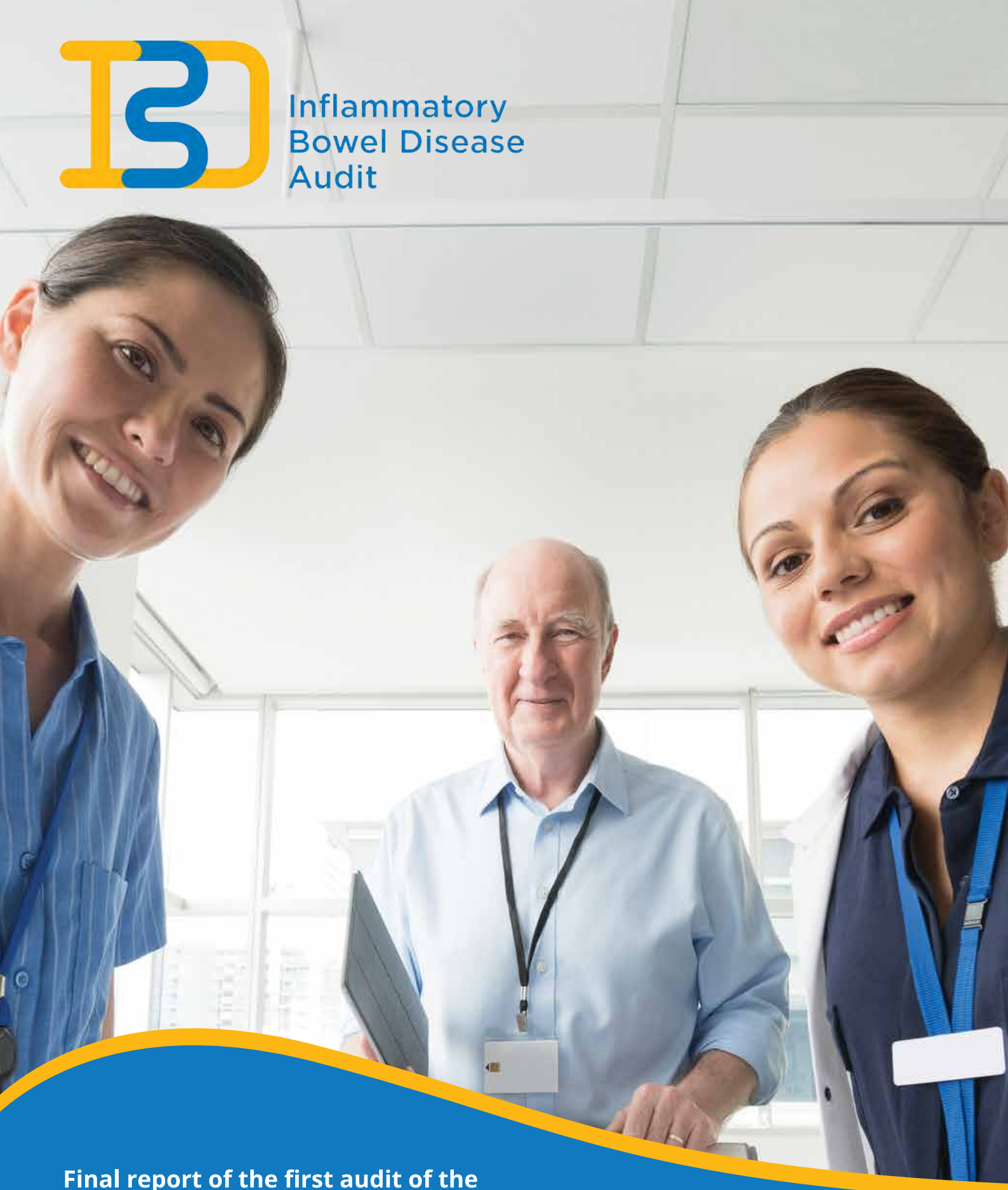
Inflammatory Bowel Disease Audit



Final report of the first audit of the organisation and provision of IBD services in Australia 2016

Inflammatory Bowel Disease Quality of Care Program

Crohn's & Colitis™ AUSTRALIA
making life more liveable

Inflammatory Bowel Disease Audit

Crohn's & Colitis Australia (CCA) is a not-for-profit organisation that supports 75 000 people living with Crohn's disease and ulcerative colitis. Established in 1985 the organisation delivers support programs such as education, advocacy, counselling, increasing awareness, and generating and utilising funds for research and support. CCA, the peak national group representing people with inflammatory bowel disease (IBD), engages with the key stakeholders in IBD care and services including its members, others living with IBD, medical and healthcare professionals and their representative bodies, hospitals, primary health, State and Commonwealth governments, industry groups and the broader health advocacy sector. Visit **www.crohnsandcolitis.com.au** for more information about this audit or CCA's programs and services.

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Inflammatory Bowel Disease Audit

Table of contents

Acknowledgments Page 4
Key Findings Page 6
Executive Summary Page 7

Section 1
Introduction Page 11
The imperative to improve IBD care across Australia Page 11
The IBD Quality of Care Program Page 12
Establishing IBD standards of care for Australia Page 13
The NICE IBD quality statements Page 13
Conduct and design of the first national IBD Audit Page 14
Structure of the report Page 15
Detailed IBD Audit method Page 16

Section 2 Summary results and recommendations
A national snapshot of IBD care - AIHW data Page 20
Key findings of the IBD audit Page 23
Recommendations Page 27
Participation (Organisational Audit) Page 30
Hospital activity (Organisational Audit) Page 33
Measuring IBD services against the Interim IBD Standards Page 35

Section 3 Full results tables
Organisational Audit data tables Page 42
Clinical Audit data tables Page 59
Crohn's disease data tables Page 59
Ulcerative colitis data tables Page 76

References Page 94

Appendixes
Appendix 1 - Participating sites Page 95
Appendix 2 - Survey questions Page 97

Acknowledgments

CCA gratefully acknowledges the generosity of the UK Royal College of Physicians for providing access to their audit questionnaires and project advice, along with the Stroke Foundation – Australia for their project advice.

Very special thanks go to the 219 hospital staff and auditors who gave their time to complete the audits voluntarily. In most cases this work was in addition to substantial clinical workloads. It is a testament to their genuine commitment to improving the quality of life of patients with inflammatory bowel disease and their families throughout Australia.

Thanks also to Ms Megan Reyneke and Dr Monique Kilkenny of the Translational Public Health and Evaluation Division, Stroke and Ageing Research Group, School of Clinical Sciences at Monash Health, Monash University for their statistical data analysis services, advice on survey design and tabulation of results for national and individual site reports.

The web-based data collection tool was developed and maintained by Netsolving Ltd.

The IBD Audit and this publication have been made possible through the support of the Australian Government Department of Health, Crohn's & Colitis Australia and unrestricted educational grants from Janssen (Janssen-Cilag Pty Ltd.) and Ferring Pharmaceuticals.

The IBD Audit is an element of CCA's IBD Quality of Care Program which has been overseen by a multi-organisational steering committee. Grateful thanks go to the peak bodies that have supported the program and their representatives - individuals who have devoted considerable time, knowledge and expertise throughout the program.

IBD Quality of Care Steering Committee representatives:

Professor Paul Pavli (Chair) - Director, Crohn's & Colitis Australia
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APS Australian Psychological Society

Crohn's & Colitis Australia making life more liveable

CSSANZ Colorectal Surgical Society of Australia and New Zealand

DAA Dietitians Association of Australia

GENCA

GESA Gastroenterological Society of Australia

Pharmaceutical Society of Australia

RACP Specialists. Together

Royal Australasian College of Surgeons

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Inflammatory Bowel Disease Audit

KEY FINDINGS

2012-2013

AUSTRALIA **5460** overnight admissions for IBD

HIGH BURDEN OF DISEASE

60% aged 39 years or less

54% (CD) **44%** (UC) had the disease for more than 5 years

60% admitted via emergency department

25% readmitted within the last 30 days

1 IN 3 anaemic on admission

1 IN 5 required surgery

HOSPITALS: CARE IS VARIABLE

1% had a full IBD team

24% had at least a Partial IBD Service

39% IBD nurse

51% IBD helpline

4% Psychologist

38 - 40% had nutrition screening on admission

<28% had a protocol for management of acute severe Ulcerative Colitis

IBD SERVICES MORE LIKELY TO DELIVER BETTER QUALITY CARE

15 - 17% fewer admissions via Emergency Department

More multidisciplinary teams

92% VS 53% Improved safety monitoring of biologic drugs

84% VS 54% Improved safety monitoring of immunosuppressive drugs

- Greater use of laparoscopic surgery
- Fewer CT scans (radiation exposure)
- More patient education materials and advice

Executive summary

The problem

Crohn's disease and ulcerative colitis, known collectively as the inflammatory bowel diseases (IBD), are life-long gastrointestinal disorders. The acute symptoms may be extremely distressing and can result in significant social stigma and isolation. Their chronic relapsing nature has broader effects on an individual's emotional, physical and societal wellbeing. That these conditions affect mainly young people at the time when they are establishing their careers and relationships is of particular concern.

These conditions result in significant costs to society each year: hospital costs for 2012 were estimated to be over $100 million; productivity losses, over $380 million; and total indirect costs over $2.7 billion.[1]

There have been many advances in management over the last decade, particularly in understanding the importance of a multidisciplinary team approach, the use of novel biological agents and the implementation of new surgical techniques. These advances in care have yielded important gains for patients and for the community, but there is evidence that the standard of care is inconsistent across Australia.[1]

The project

In response to feedback from members and stakeholders, and in the absence of national data to inform the delivery of care to people with IBD, CCA undertook to develop national standards, and to perform an audit of hospitals providing IBD services.

The survey of Australian hospitals took place in two stages:

1. Organisational Audit - a one-off survey completed by participating hospitals focused on the activity, organisation and resourcing of IBD services.

2. Clinical Audit - an audit of inpatient records examining the delivery of services to people with IBD admitted to participating hospitals.

Key findings

A total of 138 hospitals identified from the Australian Institute of Health and Welfare (AIHW) public hospital listing 2012-2013 were invited to participate:[2] 71 contributed to the Organisational Audit; of these, 52 also undertook the Clinical Audit.

The results can be summarised in three themes:

- There is a high burden of disease, particularly in those under 40 years of age

- Care is inconsistent and documentation is poor across sites

- Full IBD teams rarely exist in Australia yet sites with even a Partial IBD Service deliver better quality care. Partial IBD Service is a modest service level descriptor defined as at least a 0.4 full-time equivalent (FTE) IBD nurse, a named clinical lead and an IBD helpline. This is an alternative to the full IBD team (defined in the Interim Australian IBD Standards 2015)[3] which was so rare in Australia that it was not a suitable domain for analysis.

There is a high burden of disease, particularly in those under 40 years of age

The clinical audit of 1440 hospitalised patients (26% of the total national IBD admissions over the same time period) indicated that around 60% were in their 30s or younger and 10% were under 18 years of age. Their average length of hospital stay was 8 days.

Over 60% were admitted as emergencies because of active disease, over 40% had had admissions in the previous 2 years and of those a quarter had had an admission in the preceding month.

More than one in five patients suffering from Crohn's disease had surgery and over one in six patients suffering from ulcerative colitis had surgery, generally involving the removal of the colon (large bowel).

"I was 15 or 16 when I first started experiencing symptoms of Crohn's. But it hit me very, very badly on my 21st birthday. I remember I had to go to the toilet 25 times and I was very fatigued and ended up in hospital. Just one week after my birthday, I had dropped from 89 to 68 kilos. It took another 6 months until I was diagnosed."

Levon Bakalian, living with Crohn's disease.

Care is inconsistent and documentation is poor across sites

There were important differences in staffing between the 71 participating sites. Only one site had a full multidisciplinary IBD team as defined in the Interim Australian IBD Standards 2015 and 17 sites offered a Partial IBD Service (24%). An IBD nurse was on the staff of only 39% of sites. An IBD Helpline was available at half the participating sites.

Despite the availability of evidence-based guidelines, few sites had management protocols in place. Documentation of fundamental factors in IBD care was incomplete and inconsistent in the audited records. Nutritional assessment, generally, was suboptimal. Only two in three people discharged on immunosuppressive medication with potentially serious side-effects had a plan for safety monitoring.

Less than 5% of the sites had a mental health clinician in their IBD service even though a psychological condition was the most frequently occurring comorbidity (over 25%). Moreover, when mental health care was provided, it was often delivered by a social worker rather than a psychologist or psychiatrist.

Partial IBD Services deliver better quality care

There were differences in structure, processes and important outcomes when the 17 sites with a Partial IBD Service were compared to those without any available services. One of the most striking differences was a 15-17% reduction in the number of admissions through the emergency department in those sites with a Partial IBD Service.

Multidisciplinary assessment was more likely to occur at sites that have the resources and roles to meet the needs of people with these complex diseases and can manage the new and evolving treatment options.

Sites with a Partial IBD Service were also more likely to have:

- appropriate investigation and management particularly with the use of immunosuppressive and biological medications
- higher levels of safety monitoring of immunosuppressive and biological medications
- access to specialised surgery and its perioperative management
- better documentation in the clinical record
- consistently provided patient education materials and advice.

Partial IBD Services were also more likely to provide access to newer forms of therapy in clinical trials than those without any service.

The solution

The national IBD Audit highlights many deficiencies in the delivery of IBD care across Australia and, more importantly, has shown that a number of simple and practical recommendations can provide significant benefits to patients and savings to the healthcare system.

> "Good organisation of IBD care is not an optional extra and will have a greater impact on overall standards of care than novel therapy for a minority."
>
> Professor Simon Travis, Radcliffe Hospital, Oxford Translational Gastroenterology Unit

The priority recommendations follow:

Recommendation 1
Hospitals should be funded, and should make funding internally available, to provide the resources required to deliver IBD services according to the Australian IBD Standards 2016.[4]

Recommendation 2
IBD services should adopt a multidisciplinary approach and nominate a clinical lead with the skills, authority and resources to realise improvement in care.

Recommendation 3
IBD nurse roles should be incorporated into all IBD services in line with the proven benefit and Australian IBD Standards 2016.

Recommendation 4
All IBD services should implement responsive telephone and email helplines.

Recommendation 5
All specialised IBD surgery should be performed at sites with a full multidisciplinary team experienced in the assessment and management of people with IBD.

Recommendation 6
Hospitals with low IBD admission rates should review their systems to ensure that people presenting with IBD receive the breadth and quality of services described in the Australian IBD Standards 2016 on site or via clear referral and support pathways.

Recommendation 7
All hospitals caring for people with IBD should have, and should encourage, access to dietitians with specialised knowledge of IBD. Nutrition risk screening should be part of the assessment of all people with IBD.

Recommendation 8
All hospitals caring for people with IBD should ensure they have the means to undertake mental health screening and to deliver psychological support when needed.

Recommendation 9
All hospitals caring for people with IBD should review their medication information, monitoring and surveillance protocols and practice and ensure they are in line with the Australian IBD Standards 2016.

Recommendation 10
All hospitals caring for people with IBD should evaluate their clinical IBD documentation practices and ensure systems for policy and protocol development, audit and data review are in place to measure and improve quality of care.

Recommendation 11
IBD services should develop processes to engage people with IBD and their carers in decisions about their care and the IBD service.

Recommendation 12
A survey of people living with IBD should be undertaken to identify the source of variation in care as it relates to the prevailing standards.

Recommendation 13
CCA should be funded to continue the quality improvement cycle by repeating the IBD Audit to measure change and identify new or ongoing variation in IBD care.

"It's great, you can see your gastroenterologist, then fit in a visit with the dietitian, or get some time to just talk through the emotional side of things."

Kelsie Dummett about the Mater Young Adult Centre IBD service

Section 1

Introduction

Crohn's disease and ulcerative colitis are life-long gastrointestinal disorders that commonly present in adolescence and early adulthood. Collectively known as the inflammatory bowel diseases (IBD), the conditions are an established global problem, and Australia has among the highest prevalence in the world. More than 75 000 Australians live with IBD.[1]

The hallmark of these diseases is inflammation of the gut, affecting the colon alone in ulcerative colitis, or anywhere along the gastrointestinal tract in Crohn's disease. The bowel becomes red, hot, swollen, tender and does not function normally. This dysfunction can cause a range of problems that include diarrhoea, pain, bleeding, profound fatigue, weight loss, anaemia and bowel obstruction. The disease can become so severe that hospitalisation is required and many people affected by IBD require surgery. The acute symptoms may be extremely distressing and affect an individual's ability to work, study and establish relationships. Put simply: to function normally. Malnutrition is a common complication and is a cause of poor patient outcomes,[5] particularly for those who undergo surgery.[6] Those affected may also develop other complications that are potentially life threatening, and there are links between IBD and an increased risk of colorectal cancer.

All the medications used to treat IBD have potentially severe side-effects and significant associated risks. For example, being on corticosteroid therapy is regarded as worse than the disease itself by many patients.

The immunosuppressive medications and biological agents need close monitoring for rare but potentially life-threatening complications. There are many misconceptions about these conditions, particularly relating to surgery and the need for stoma therapy (bags).

The chronic relapsing nature of IBD has broader effects on an individual's emotional, physical and social wellbeing. Even when enjoying good health, people with IBD may be concerned about their future, given the unpredictability of its clinical course and the variation in the severity and pattern of disease. That these conditions affect mainly young people at the time when they are establishing their careers and relationships is of particular concern.

The imperative to improve IBD care across Australia

In 2012 in response to CCA member feedback on the variable experience of the quality of care and stakeholder feedback on the limitations of IBD services, particularly in relation to resourcing, CCA commissioned PricewaterhouseCoopers (PwC) to assess IBD service models in Australia. The resulting 2013 report, *Improving Inflammatory Bowel Disease Care Across Australia*, found that there is an increasing burden of disease for individuals and the nation.[1] The report proposed that improvements in the quality of care could alleviate this burden.

The prevalence of IBD in Australia is increasing: PwC calculated it to be between 68 000 and 84 000 at June 2012. It is estimated to increase to almost 100 000 in 2022 (Table 1).

Table 1 Projected prevalence of IBD 2013-2022

	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Lower	69 215	70 392	71 588	72 805	74 043	75 302	76 582	77 884	79 208	80 475
Upper	85 088	86 535	88 006	89 502	91 024	92 571	94 145	95 745	97 373	99 028

Source: PricewaterhouseCoopers Australia (PwC). Improving Inflammatory Bowel Disease Care Across Australia. March 2013.[1]

In addition, the report noted that there was broad agreement that the severity of the condition had worsened and that the onset was most prevalent early in adulthood.[7]

The PwC report identified two important problems in Australia: increased costs of healthcare utilisation and inadequate and inconsistent care.

The 2012 hospital costs attributable to IBD were estimated to be in the order of $100 million. Productivity losses (including loss of earnings, absenteeism and premature death) totalled more than $361 million for 2012. In addition the report identified other costs associated with taxation revenue impact, carer costs, out-of-pocket expenses, deadweight losses, welfare costs and loss of wellbeing at over $2.7 billion for the year. While the report acknowledges pockets of excellence in dedicated IBD services, it found that even those sites were hampered by disparate and insecure funding. In regions without specialised IBD services there was a lack of access to gastroenterologists and other clinicians resulting in inadequate understanding of the condition and its treatments.

PwC advised that addressing the problems associated with the prevailing care approaches have been shown to result in:[1]

1. Improvements in costs and healthcare utilisation through:
    - a reduction in avoidable admissions and saved bed days
    - productivity gains for patients and carers
2. Better service integration and patient experience through:
    - coordination of appropriate and timely care
    - access to education and support.

Among a range of options proposed to address the current issues facing IBD care in Australia, PwC detailed the positive outcomes of a range of activities undertaken in the UK to inform a more appropriate model of care and to understand where value can best be delivered to the health system. Activities involved assessing the structure, process, outcome and organisation of care, as well as establishing a system of measurement to allow for the comparison and improvement of quality of care.

The IBD Quality of Care Program

Responding to the PwC report, CCA sought the support of the Australian Government Department of Health and corporate partners, Janssen and Ferring, to undertake a national audit of hospitals delivering IBD services and to inform a nationally consistent response to improve the quality of IBD care through the development and acceptance of a multidisciplinary Australian Standards of IBD Care document, known as the IBD Quality of Care Program.

The ultimate aims of the program are:

- to optimise the consistency, quality and safety of care for all IBD patients throughout Australia by examining the local provision and organisation of IBD care
- to provide an evidence-based case for the allocation of IBD resources that is consistent with national needs, is supported by clinical and patient stakeholder groups and aligns with government policy objectives.

A multi-organisational Inflammatory Bowel Disease Quality of Care Steering Committee (IBD QoC Steering Committee) was established with representation from CCA, Royal Australasian College of Physicians, Gastroenterological Society of Australia, Royal Australasian College of Surgeons, Gastroenterological Nurses College of Australia, Dietitians Association

of Australia, Colorectal Surgical Society ANZ, Royal Australian College of General Practitioners, Australian Psychological Society and Pharmaceutical Society of Australia.

CCA with the support of the IBD QoC Steering Committee commenced the project in October 2014.

Establishing IBD standards of care for Australia

In order to identify the factors that contribute to variation in care, the characteristics of a service that will result in high quality care must be identified. In Australia there were no published standards or guidelines that could be used as a point of reference for audit of IBD services. As recommended by PwC, the IBD QoC Steering Committee elected to develop a set of national standards which drew on the considerable work undertaken by the IBD Standards Group in the UK. This group has published the *Standards for the healthcare of people who have inflammatory bowel disease. 2013 Update* that built upon their previous standards and three rounds of auditing of IBD care in the UK over the preceding 7 years.[8]

The IBD QoC Steering Committee adopted the six overarching domains of the UK IBD Standards, but substantially modified the implementation detail in response to the Australian setting. The main factors compelling adaptation included:

- State-based service structural and funding variations
- The dual public and private healthcare funding system
- The expansive geography covered by healthcare services.

The multidisciplinary standards were reviewed by a focus group made up of people living with IBD and their carers and were modified according to their feedback. Overwhelmingly the participants of the focus group welcomed the content of the Standards including the importance of a responsive service system, emphasis on education and support and suitable arrangements for the care of children.

> Focus Group participants described their own healthcare experiences with IBD and rated that experience. None of the participants rated their experience as 'excellent'. Three of the participants rated their experience as 'poor', and three as 'average/good enough'. One participant said her new gastroenterologist was starting to increase her rating to better than 'good enough'.
>
> Facilitator, CCA IBD Quality of Care focus group 2015

In October 2015 the Interim Australian IBD Standards were published for public review and trial through audit. The Standards specify consistent expectations for IBD care for hospitals, healthcare professionals, IBD stakeholders and people living with IBD. They provide the benchmark for audit of Australian IBD services. Revision of the Standards post trialling is now complete and publication of the Australian IBD Standards 2016 coincided with the publication of this report.

The Australian IBD Standards 2016 are consistent with the NICE quality statements

The NICE IBD quality statements

The UK National Institute for Health and Clinical Excellence (NICE) was originally established in 1999 as the National Institute for Clinical Excellence, a special health authority to reduce variation in the availability and quality of National Health Service (NHS) treatments and care. In April 2013 NICE was established in primary legislation, becoming a non-departmental public body and taking on responsibility for developing guidance and quality standards in social care. As a non-departmental public body, NICE is accountable to the Department of Health, but operationally independent of government.

The four NICE quality statements regarding IBD[9]

1. People with suspected IBD have a specialist assessment within 4 weeks of referral.

2. Services provide age-appropriate support from a multidisciplinary team for people with IBD, and their family members or carers.

3. People having surgery for IBD have it undertaken by a colorectal surgeon who is a core member of the IBD multidisciplinary team.

4. People receiving drug treatment for IBD are monitored for adverse effects.

Conduct and design of the first national IBD Audit

The IBD QoC Steering Committee and CCA project team developed the methodology for the first Australian IBD Audit in 2014-15.

The audit objectives were to:

- characterise the variability in current IBD care and resources

- identify the source of variations if found.

Hospitals were invited to participate in a survey of their IBD organisation and activity (Organisational Audit) for the period December 2013 to November 2014, and to perform a clinical audit of IBD patient records for the corresponding timeframe (Clinical Audit). Surveys were designed to align with the Interim Australian IBD Standards 2015.

Structure of the report

A detailed description of the methodology of the IBD Audit is presented in Section 1.

Section 2 provides a summary of results and recommendations. National data sourced from the Australian Institute of Health and Welfare (AIHW) are presented to provide context for the IBD Audit sample. Participation in the audit, hospital activity and the main findings of the collective Clinical and Organisational Audits and recommendations are summarised. Data are also presented as they relate specifically to the Interim Australian IBD Standards 2015.

Section 3 contains the full Organisational Audit result tables arranged as they relate to the Interim Australian IBD Standards 2015. The Clinical Audit result tables that relate to the actual care delivered are presented separately for Crohn's disease and ulcerative colitis.

Site-specific data along with peer comparator data will be forwarded directly to each participating site for internal quality improvement purposes but do not form part of this report.

Detailed IBD Audit method

The IBD Audit surveyed Australian hospitals in two stages:

- Organisational Audit - a one-off survey completed by participating hospitals focused on the activity, organisation and resourcing of IBD services at their site
- Clinical Audit - an audit of inpatient records examining the delivery of services to people admitted to participating hospitals for IBD management.

Audit governance and ethical considerations

Guidance was sought from the National Health and Medical Research Council (NHMRC) on the ethical considerations for the proposed audit.[10] This advice indicated that:

1. Clinical audit represents a Quality Assurance (QA) activity with the primary purpose 'to monitor or improve the quality of service delivered by an individual or an organisation'.
2. There is no formal Human Research and Ethics Committee (HREC) review required for such activities; appropriate oversight of QA activities is adequate.

This advice was communicated to participating hospitals and most sites did not undertake local HREC review. Some sites had local or regional policies that necessitated HREC review for participation in any multisite data collection project.

The audit was led by CCA and was overseen by a subcommittee of its Board, the IBD QoC Steering Committee. The Committee included nominated members representing the peak stakeholder bodies in IBD care in Australia. CCA project staff were accountable to the CEO of CCA.

Sites for the Organisational and Clinical Audits

Hospitals identified from the Australian Institute of Health and Welfare public hospital listing 2012-2013 were invited to participate in the audit.[2] The intention was to audit up to 100 hospitals of varying size and remoteness that delivered some level of service to IBD patients. One hundred and thirty-eight hospitals were invited to participate in the IBD Audit including:

- 81 major city hospitals with more than 100 beds (including 8 specialist paediatric hospitals)
- 29 inner regional hospitals with more than 100 beds
- 23 outer regional hospitals with more than 50 beds
- 5 remote hospitals with more than 50 beds.

Hospitals were excluded if they met any of the following criteria:

- Psychiatric hospital
- Aged-care and rehabilitation facility
- Private hospital providing private services only (private facilities that provide public services including gastroenterology were included)
- Women's (maternity) care hospital
- Very remote location category (which has on average fewer than 9 beds).

Hospitals that operated within networks that shared a single IBD service were permitted to register as a single site. Colocated public and private hospitals with a common IBD service were asked to only include public hospital data.

Recruitment

Hospitals were invited by letter directed to CEOs and a senior medical leader: Head of gastroenterology, gastroenterologist or Medical Director. Hospitals that did not respond were followed up by email, phone call, repeat invitation and through the communication pathways of Australian Inflammatory Bowel Disease Association (AIBDA), Gastroenterological Nurses College of Australia Inc. (GENCA) and regional health networks.

Hospital registration for the audit required a signed agreement by an authorised representative of the hospital administration, the nomination of a senior medical staff member to oversee the audit, and the nomination of a contact person.

Patient cohort sample

The Clinical Audit reviewed inpatient episodes for IBD patients at registered sites. Data were requested for the period 1 December 2013 to 30 November 2014 on a sample of up to 20-50 consecutive admissions according to a sliding scale based on hospital bed numbers. Data were reviewed from case notes.

Inclusion criteria

- Separation (discharge) date between 1 December 2013 and 30 November 2014
- Must be admitted, acute care, multiday stays (length of stay [LOS] 24 hours or more or otherwise identified as overnight admissions)
- Have a principal diagnosis (ICD-10 AM codes) of:
  - » Crohn's disease (K50.0 Crohn's disease of small intestine, K50.1 Crohn's disease of large intestine, K50.8 Other Crohn's disease and K50.9 Crohn's disease, unspecified)

    or

  - » Ulcerative colitis (K51.0 Ulcerative (chronic) pancolitis, K51.2 Ulcerative (chronic) proctitis, K51.3 Ulcerative (chronic) rectosigmoiditis, K51.4 Inflammatory polyps, K51.5 Left hemicolitis, K51.8 Other ulcerative colitis, K51.9 Ulcerative colitis, unspecified and K52.3 Indeterminate colitis.
- Multiple admissions during the audit date range for the same patient were eligible
- Patients of all ages included
- Admitted care, multiday stays in short-stay units or emergency departments were eligible.

Exclusion criteria

- Any day case LOS less than 24 hours (including infusion, endoscopy or day surgery procedure)
- Cases admitted and discharged on the same day
- Non-admitted emergency department care.

Survey tools

The IBD Audit survey tools were developed by the IBD QoC Steering Committee using the UK IBD Audit Round 3 survey questions as a starting point. Survey questions (see Appendix 2) were adapted for the Australian healthcare setting and aimed to yield data relevant to the Interim Australian IBD Standards 2015. Questionnaires were trialled by IBD QoC Steering Committee members, project staff and hospital sites before translation into a web-based format.

Netsolving, a UK-based specialist clinical audit software developer, created the online Organisational Audit and Clinical Audit surveys.
Four web survey tools were created:

- Organisational Audit for specialist paediatric hospitals
- Organisational Audit for adult hospitals (includes hospitals that also provide services to paediatric patients)
- Clinical Audit Crohn's disease (with variant questions for adults and under 18 years)
- Clinical Audit ulcerative colitis (with variant questions for adults and under 18 years)

User acceptance testing was undertaken by the project staff and one site before audit launch.

Data collection

Each registered site nominated a single contact person to ensure the completion of data collection at their site. The Organisational Audit required a hospital staff member with knowledge of the processes involved in service delivery to IBD patients in 2014 to be nominated as auditor. Possible auditors included gastroenterologists, department heads, IBD nurses and health-service managers. In most instances, health-information staff were also involved in the provision of coding data, which formed part of the Organisational Audit. The Clinical Audit required the nomination of a hospital staff member with clinical auditing capability. There was no requirement that the same site auditor undertake both the Organisational and Clinical Audits.

Auditors were required to log in to the secure, password-protected ibdaudit.com.au website and complete the questions for the relevant survey.

Confidentiality was maintained through use of site codes for registered hospitals and case IDs for patient admission details. No patient identifying details were exported from sites for data analysis.

In addition to the patient file sample requested, up to five repeat file audits were requested from each site for reliability testing. Repeat audit file data are not reported in the results but will be used to improve future questionnaires.

Errant data were minimised through the use of inbuilt data verification and logic checks. The web tool included help notes for relevant questions that clarified the nature of the data being sought.

Organisational survey data were collected between 15 December 2015 and 29 April 2016. Clinical Audit data were collected between 29 February 2016 and 6 June 2016.

Training and support

Educational materials were produced for site auditors to support them in the use of the web tool. This educational support included information and instruction documents and screen capture videos. In addition an email and telephone helpdesk were staffed by CCA to support web-tool users and solve data entry problems.

Data analysis

Staff from the Translational Public Health and Evaluation Division, Stroke and Ageing Research, School of Clinical Sciences at Monash Health, Monash University analysed the data. To ensure confidentiality, data were de-identified before transmission to Monash University. A hospital site identification number enabled the provision of local reports to the individual participating sites.

Data verification was undertaken collaboratively by Monash University and CCA using programmed data logic checks.

The data were analysed using computer programs including Intercooled STATA 12.1 for Windows and Microsoft Excel 2013. The data were exported from the web-based database as an Excel spreadsheet and transferred into STATA. All clinical data were aggregated to provide national estimates and variables were summarised according to a range of domains.

A number of participating sites (n=32) agreed to enter patients' medical record information using two different auditors for the Clinical Audit. This action determined whether or not a medical record audited independently by two people provided the same responses. These data are not reported in this report but the information obtained will be used to refine and improve future audit cycle questionnaires.

Section 2 Summary results and recommendations

A national snapshot of IBD Care – Australian Institute of Health and Welfare (AIHW) data

A snapshot of IBD hospital care was provided by AIHW from a customised report of the National Hospital Morbidity Database. This overview helps place the results of the IBD Audit in context.

The data below comprise total public hospital activity for Crohn's disease and ulcerative colitis (principal diagnosis) for all States and Territories with the exception of the Australian Capital Territory, for the audit period 1 December 2013 to 30 November 2014.

There were 5460 overnight admissions (referred to as separations) for a principal diagnosis of Crohn's disease, ulcerative colitis or indeterminate colitis (Table 2). When including same-day admissions, the annual total was 21 386. Same-day admissions include admissions for infusional therapy (e.g. anti-tumour necrosis factor (TNF) agents, intravenous iron), endoscopic procedures and minor surgery.

Table 2 Crohn's disease and ulcerative colitis separations for all public hospitals, by State, 1 December 2013 to 30 November 2014 (AIHW data)

State	Crohn's disease – principal diagnosis		Ulcerative colitis – principal diagnosis	
	Overnight separations	Total separations	Overnight separations	Total separations
NSW	1077	3196	648	1358
NT	27	164	12	39
QLD	592	2789	533	964
SA	310	865	188	267
TAS	85	509	65	195
VIC	802	6715	630	1781
WA	288	1419	203	1125
Total	**3181**	**15 657**	**2279**	**5729**

The vast majority (over 75%) of these admissions occurred in hospitals in major cities (Table 3) as defined by the Australian Bureau of Statistics (ABS) Australian Standard Geographic Classification.

Table 3 Crohn's disease and ulcerative colitis overnight separations for all public hospitals, by remoteness category, Australia, 1 December 2013 to 30 November 2014 (AIHW data)

Remoteness	Overnight Crohn's disease (%)	Overnight ulcerative colitis (%)
Major cities	75	77
Inner regional	15	13
Outer regional	6	6
Remote Australia	1	1
Very remote	0	0
Not applicable (TAS)	3	3
Total	100	100

Over three-quarters of admissions were emergency presentations (Table 4).

One in ten of the admissions was a person under the age of 18 years.

Deaths were rare: only three were reported from 5460 admissions (excluding TAS and ACT).

Table 4 Elective status, deaths and paediatric overnight separations, for all Australian public hospitals, 1 December 2013 to 30 November 2014 (AIHW data)

Overnight separations	Crohn's disease overnight	Ulcerative colitis overnight
	n/N (%)	n/N (%)
Emergency	2449 / 3181 (77)	1732 / 2279 (76)
Elective	692 / 3181 (22)	496 / 2279 (22)
Age < 18 years	361 / 3181 (11)	229 / 2279 (10)
Deaths	1 / 3181 (0)	2 / 2279 (0)

Common IBD-related surgeries (AIHW data)

A total of 249 (Crohn's disease) and 193 (ulcerative colitis) common IBD-related surgical procedures completed during these admissions.

Length of stay (AIHW data)

The median of the average length of stay (ALOS) reported for each hospital was 5.2 days for Crohn's disease and 6.5 days for ulcerative colitis. Note that the ALOS is not provided by AIHW where total overnight separations for the selected principal diagnosis in a particular hospital were less than 10 (about half the hospitals).

Admissions for people who had Crohn's disease or ulcerative colitis managed as either an additional diagnosis or principal diagnosis are represented in Table 5.

Table 5 Crohn's disease and ulcerative colitis separations as additional or principal diagnosis, for all Australian public hospitals, 1 December 2013 to 30 November 2014 (AIHW data)

State/ Territory	Crohn's disease		Ulcerative colitis	
	Overnight separations	Total separations	Overnight separations	Total separations
NSW	1893	4382	1027	2033
NT	44	186	21	60
QLD	1037	3672	783	1349
SA	540	1186	260	353
TAS	175	661	95	266
VIC	1382	7696	886	2394
WA	558	1930	281	1455
Total	**5629**	**19 713**	**3353**	**7910**

ACT: Data not available

Key findings of the IBD Audit

Seventy-one sites participated in the Organisational Audit and, of these, 52 also participated in the Clinical Audit. Characteristics of the sites can be reviewed under the Participation heading of this section.

Analysis of the IBD Audit data provide a narrative that can be summarised in three themes:

- There is a high burden of disease, particularly in those under 40 years of age.
- Care is inconsistent and documentation is poor across sites.
- Full IBD teams rarely exist in Australia yet sites with even a Partial IBD Service deliver better quality care than sites with no IBD service at all.

There is a high burden of disease, particularly in those under 40 years of age

The CCA IBD Audit examined a sample of 1440 inpatients of whom over 60% were in their 30s or younger and 10% were under 18 years of age. The average length of stay for these patients was 8 days.

The audit sample represents a substantial subset (26%) of the total 5460 overnight admissions for IBD captured by the AIHW during the same timeframe.

The majority of patients (60%) were admitted as emergencies because of active disease. Over 40% had had admissions in the preceding 2 years and a quarter of those had an admission in the preceding month. Patients who were seen as outpatients attended a median of three times (interquartile range 2-5) in the 12 months before admission, and approximately half had active disease at the review preceding admission to hospital.

About 50% of the audited cohort had IBD disease duration longer than 5 years.

Over a third of patients were anaemic on admission, with even higher rates seen in those under 18 years of age admitted for Crohn's disease (48%).

Nearly half of these young patients had other significant medical problems, the most common of which was a psychological condition.

Despite modern medical therapies, more than one in five patients admitted with Crohn's disease had surgery, generally for bowel obstruction, the drainage of an abscess, or failure of medical therapy. Similarly, over one in six patients admitted for ulcerative colitis had surgery, which generally involved colectomy (removal of the large bowel).

Most patients (80%) were discharged on ongoing treatment to improve symptoms or long-term maintenance medications with significant risks of side-effects. These agents included corticosteroids (e.g. prednisone), immunosuppressive drugs (e.g. azathioprine) and biological agents (e.g. infliximab and adalimumab).

Care is inconsistent and documentation is poor across sites

There were significant differences in staffing between different sites:

- 80% had a gastroenterologist
- 63% had a colorectal surgeon
- 39% had an IBD nurse on staff
- Only one site had a full IBD team as defined in the interim Australian IBD Standards 2015.

These differences were more pronounced when hospital activity was considered: less than half (48%) of the low IBD activity sites (1-49 IBD admissions for the audit year) had a gastroenterologist on site compared to almost all (95%) the highest IBD activity sites (100+ admissions for the audit year). Similarly, one third (32%) of low IBD activity sites had a colorectal surgeon on staff, compared to 78% of the highest IBD activity sites. The figures for an IBD nurse were 14% and 65% respectively. Overall, fewer than one in five patients saw an IBD nurse during their admission: 16% (Crohn's disease) and 18% (ulcerative colitis). An IBD Helpline was only available at half the sites (51%).

IBD nurses were not available at all specialist paediatric sites: only one third had ongoing funded positions.

There were also very important variations in management:

- Despite the existence of widely accepted evidence-based guidelines for the management of acute severe ulcerative colitis, only one in four sites (28%) had a protocol in place for such patients.
- Prophylaxis for venous thromboembolic disease was administered to only 72% of Crohn's disease and 77% of ulcerative colitis patients across all sites.
- Although over half of audited cases (58% Crohn's disease; 47% ulcerative colitis) were discharged on immunosuppressive medication, which mandates a long-term safety monitoring protocol, only two in three (67% Crohn's disease; 64% ulcerative colitis) had such a plan documented.

The audit observed also that there were low rates of nutritional screening and dietetic intervention pre and postoperatively. Nutritional assessment, generally, was also suboptimal: less than half (44% Crohn's disease; 42% ulcerative colitis) saw a dietitian during admission; less than half (40% Crohn's disease; 38% ulcerative colitis) had a nutritional risk screen during their admission; and only 56% (Crohn's disease) and 44% (ulcerative colitis) of those for whom nutritional supplementation was recommended on discharge were followed up by a dietitian. The use of dietary therapy was rarely reported among patients at admission (1%).

Other important aspects of management also varied significantly between sites. For example, less than 5% had a mental health clinician in their IBD service even though a psychological condition was the most frequently occurring comorbidity (30% Crohn's disease; 25% ulcerative colitis). Less than a quarter of these patients received psychological support during their admission (25% Crohn's disease; 21% ulcerative colitis). When care was provided, it was most often delivered by a social worker, rather than by a psychologist or psychiatrist.

Although 57% of sites stated that bone densitometry was offered routinely to all patients who had received more than 3 months of corticosteroids, the Clinical Audit demonstrated that only 9% (Crohn's disease and ulcerative colitis) of such patients actually had documented in the hospital records, a bone density assessment in the previous 5 years.

Documentation was considered to be substandard across sites. The Clinical Audit demonstrated that fundamental aspects of history, examination and the results of important tests were not recorded in many cases. For example, the extent of disease was recorded in only 63% (Crohn's disease) and 53% (ulcerative colitis) of previously diagnosed adult cases within 24 hours of admission, and disease severity was formally scored (using the paediatric Crohn's disease activity index [PCDAI]) for only 6% of paediatric patients.

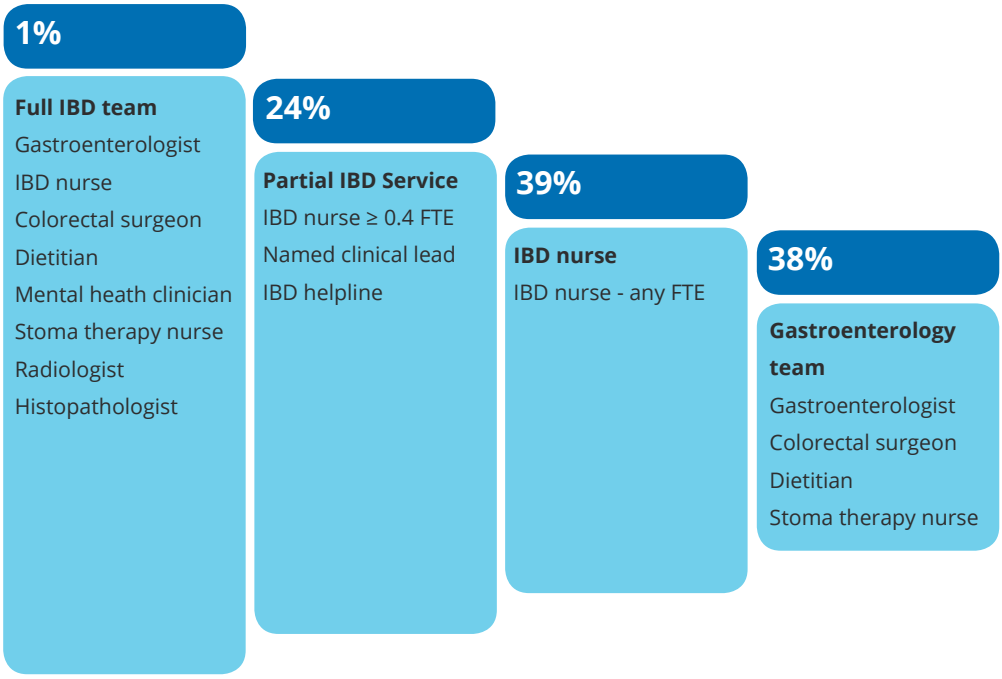
Other important aspects of history and examination that were not documented in approximately a third of patients including duration and extent of disease, stool frequency, presence of blood and smoking status. In terms of the physical examination, 40% of subjects did not have a record of weight and 60% had no recorded body mass index (BMI).

Partial IBD Services deliver better quality care

The 17 sites (24%) with Partial IBD Services were defined as having at least 0.4 EFT IBD nurse, a named clinical lead and an IBD helpline. This diluted service definition, as compared to the full IBD team defined in the Interim Australian IBD Standards 2015, had to be adopted for statistical analyses, as there was only a single site meeting the full standard. All 17 participating sites with a Partial IBD Service were located in major cities, while a quarter of IBD admissions occurred in sites outside major cities.

There were significant differences in a number of important structures, processes and outcomes among adult sites when those with a Partial IBD Service were compared to those without any IBD service.

Partial IBD Service sites had a 15-17% reduction in the number of admissions via the emergency department (59% vs 76% for Crohn's disease and 57% vs 72% for ulcerative colitis.) This finding has major implications for both the patient experience and for hospital resources.



FTE: full-time equivalent

Multidisciplinary assessment was much more likely to occur at Partial IBD Service sites. Combined medical and surgical outpatient reviews of appropriate cases occurred in 59% vs 12% of sites with a Partial IBD Service compared to those without. Regular multidisciplinary meetings to consider complex inpatient cases took place in 88% vs 28% of sites respectively.

Implementation of safety monitoring post discharge for immunosuppressive and biological medications was significantly better in Partial IBD Service sites. For example, a plan for safety monitoring for biological agents in Crohn's disease was implemented in 92% of Partial IBD Service sites compared to 53% of sites without. The figures for immunosuppressive drugs were 83% vs 54% respectively.

For ulcerative colitis patients, surgery was almost twice as likely to be performed laparoscopically at an IBD Centre: 54% vs 29%. For many IBD-related surgical procedures, laparoscopic or laparoscopic-assisted surgery is the standard of care.[11-13]

Various aspects of management, including the appropriate use of tests and imaging were also significantly better in Partial IBD Service sites. Abdominal CT scanning was less frequently conducted for adults with Crohn's disease at sites with a Partial IBD Service: 31% vs 46%. There is increasing awareness of the long-term consequences of radiation exposure in this young patient population who may require frequent hospitalisation and repeated episodes of medical imaging.

Partial IBD Service sites were more likely to provide access to clinical trials for patients than those without a Partial IBD Service (88% vs 31%). Searchable databases were present in only 25% of sites without a Partial IBD Service compared to 82% of sites with. Only sites with a searchable database are equipped to undertake regular and reliable self-audit and practice review.

There is also evidence that the patient experience was improved at sites with a Partial IBD Service or access to IBD nurses. Important patient information was more commonly provided in sites with an IBD nurse than in those without:

- Routine provision of educational material to newly diagnosed people (96%; 64%)
- Offer of a patient education session to newly diagnosed people (85%; 5%)
- Provision of written information about whom to contact in the event of a relapse (100%; 44%)
- Availability of information about IBD in pregnancy and its effects on fertility (77%; 46%).

Many aspects of record keeping were better in sites with a Partial IBD Service with documentation of disease extent, weight, and nutritional assessment by a dietitian, statistically significantly higher at these sites.

The average length of stay was not significantly different between sites with and without Partial IBD Services. However Partial IBD Services had higher acuity patients as supported by the greater number (estimated median) of patients receiving infliximab for Crohn's disease (indirect evidence of greater acuity) which was approximately double in sites with an IBD nurse compared to sites without: 18% vs 10% (Organisational Audit data).

In terms of clinical outcomes, it is important to note that in addition to the significant reduction in admissions through the emergency department (15-17%), and the implications for hospital resources and the patient experience, the differences between those sites with and without a Partial IBD Service correspond well to the quality statements regarding IBD care endoresed by NICE.

Recommendations

This audit has identified a range of opportunities for improvement in the quality of care for people living with IBD. If anything, the results present an overly positive picture because of positive participation bias by units with an existing interest in IBD quality of care and a negative participation bias by sites citing lack of necessary resources.

The Australian IBD Standards 2016 were informed by the audit data and the recommendations are supported by audit outcome measures.

The Standards provide an evidence-based framework for the improvement of the quality of care for people with IBD. This audit demonstrates that many hospitals do not meet these Standards. Furthermore, participating hospitals now have site-specific reports to advocate for and inform local quality improvement.

Recommendation 1
Hospitals should be funded, and should make funding internally available, to provide the resources required to deliver IBD services according to the Australian IBD Standards 2016.

Crohn's disease and ulcerative colitis are chronic relapsing conditions often resulting in repeated hospital admissions. There have been many advances in management over the last decade, particularly in understanding the importance of a multidisciplinary team approach, the use of novel biological agents, and the implementation of new surgical techniques. These advances in care have yielded important gains for patients and for the community. Optimising management requires a multidisciplinary team engaged with the patient as a part of the decision-making team. Multidisciplinary teams, team meetings and multidisciplinary clinics are often not available to people with IBD.

Recommendation 2
IBD services should adopt a multidisciplinary approach and nominate a clinical lead with the skills, authority and resources to realise improvement in care.

Hospital admissions for IBD frequently result from unplanned attendances to hospital emergency departments. Having even a modestly resourced Partial IBD Service (IBD nurse, helpline and medical lead) resulted in significantly lower rates of admission via the emergency department. The provision of a helpline is normally facilitated through the IBD nurse role. Other outcomes were also improved in sites with an IBD nurse.

Recommendation 3
IBD nurse roles should be incorporated into all IBD services in line with the proven benefit and Australian IBD Standards 2016.

Recommendation 4
All IBD services should implement responsive telephone and email helplines.

Specialised IBD surgery should be done by people with high volume experience and after discussion by a multidisciplinary team. Outcomes for colorectal surgery are likely to be improved at surgical sites using the full range of open, laparoscopic and minimally invasive techniques.

Recommendation 5
All specialised IBD surgery should be performed at sites with a full multidisciplinary team experienced in the assessment and management of people with IBD.

Many hospitals have low rates of admission for IBD treatment and from a health economics perspective cannot justify a comprehensive IBD service. Nevertheless people with IBD presenting to these hospitals should have access to high quality care as described in the Australian IBD Standards 2016.

Recommendation 6
Hospitals with low IBD admission rates should review their systems to ensure that people presenting with IBD receive the breadth and quality of services described in the Australian IBD Standards 2016 on site or via clear referral and support pathways.

Malnutrition is a cause of poor patient outcomes,[5] particularly for those who undergo surgery.[6] Malnutrition rates were high among IBD patients. Nutrition risk screening and assessment rates were low. There is a need to improve nutrition screening upon admission and before surgery, as well as to improve dietetic assessment and ongoing management.

Recommendation 7
All hospitals caring for people with IBD should have, and should encourage, access to dietitians with specialised knowledge of IBD. Nutrition risk screening should be part of the assessment of all people with IBD.

Mental health issues, especially anxiety and distress, are highly prevalent in people with IBD, which interferes with the ability to lead a normal life and creates uncertainty for those affected. These issues contribute to worse quality of life, earlier relapse, more need for inpatient care and poorer adherence to therapy, yet are not routinely addressed in current models of care.

Mental-health conditions were the most common comorbidity reported among people admitted for IBD yet provision of initial or ongoing psychological support was very low. Routine psychological screening (e.g. K10) should be completed for all IBD patients. IBD clinical staff should be aware of factors known to increase psychological distress in IBD cohorts e.g. active disease, steroids, past mental-health concerns, limited social support and hospitalisation. Indications of mental-health issues on screening tools should result in assessment and treatment by trained psychologists. There is opportunity for communication between hospital clinicians and general practitioners regarding initiation of and ongoing mental healthcare plans.

Recommendation 8
All hospitals caring for people with IBD should ensure they have the means to undertake mental health screening and deliver psychological support when needed.

The medications used in the treatment of IBD may have significant, and potentially fatal, adverse effects. These can be reduced by adequately organised and resourced safety monitoring. There was evidence that sites with a Partial IBD Service had more effective oversight of safety monitoring for both biological agents and immunosuppressive drugs.

Patient education activities were also significantly and consistently better at sites with IBD nurses, for both newly diagnosed patients, and patients on ongoing treatment.

Recommendation 9
All hospitals caring for people with IBD should review their medication information, monitoring and surveillance protocols and practice and ensure they are in line with the Australian IBD Standards 2016.

A range of processes that are important to the delivery of consistent high quality care were reported at low rates. Documentation of important clinical assessment and planning in the patient record was lacking. Standardised policies and protocols, audit and local databases were uncommon.

Recommendation 10
All hospitals caring for people with IBD should evaluate their clinical IBD documentation practices and ensure systems for policy and protocol development, audit, and data review are in place to measure and improve quality of care.

These audits described organisational and clinical IBD treatment information collected by hospital staff and healthcare professionals. Best practice quality improvement models require that the patient perspective is integrated into evaluation and that change should be measured and acted upon in a continuous cycle. CCA recognises that to provide a more complete evaluation of the organisation and delivery of IBD care it is essential to engage people living with IBD.

Recommendation 11
IBD services should develop processes to engage people with IBD and their carers in decisions about their care and the IBD service.

Recommendation 12
A survey of people living with IBD should be undertaken to identify the source of variation in care as it relates to the prevailing standards.

Recommendation 13
CCA should be funded to continue the quality improvement cycle by repeating the IBD Audit to measure change and identify new or continuing variation in IBD care.

Participation (Organisational Audit)

Of the 138 hospitals invited to participate, 83 sites formally registered to participate in the audit and 71 (Table 6) provided data for the Organisational Audit. Appendix 1 lists the participating hospitals. Sites that did not participate, most commonly cited lack of resources and staff to conduct auditing, or infrequent IBD admissions. Only 52 of the sites that completed the Organisational Audit went on to provide Clinical Audit data. Attrition was for reasons previsouly mentioned.

Five sites were designated as specialist paediatric hospitals (represented as 'paediatric' in the Survey domain) and the remainder were general hospitals that treat adults and may or may not treat paediatric patients (represented as 'adult' in the survey domain).

Table 6 Participation rates by State

State	Participating sites n (%)	Proportion of those invited (%)
ACT	2 (3)	100
NSW	22 (31)	48
QLD	15 (21)	60
SA	7 (10)	58
TAS	1 (1)	33
VIC	21 (30)	72
WA	3 (4)	19
Total	**71 (100)**	**52**

No sites from NT participated.

The size of participating hospitals (Table 7) is demonstrated by hospital bed numbers reported by AIHW Australian Hospital Statistic 2012-13. The bed capacity for two sites is unspecified for the time period (N=69).

Table 7 Size of participating sites 2012-13[2]

Size of hospital Hospital bed number	Survey		
	Paediatric	Adult	Total
	n (%)	n (%)	N (%)
0-199	1 (20)	18 (28)	19 (28)
200-399	4 (80)	20 (31)	24 (35)
400-599	0	9 (14)	9 (13)
600+	0	17 (27)	17 (25)
Total	**5 (100)**	**64 (100)**	**69 (100)**

Participating sites were categorised by the volume of IBD care delivered using hospital admission (acute separation) categories for the audit year December 2013 to November 2014 (Table 8). Sites reported their separations for the ICD-10 AM codes for Crohn's disease and ulcerative colitis. Table 9 introduces the 'IBD nurse' and 'Partial IBD Service' domains. Separation totals for two sites were not submitted (N=69).

Sites that are included in the 'IBD nurse' domain reported that they employed an IBD nurse for any number of hours regardless of whether or not there was secure funding for the position.

Sites included in the 'Partial IBD Service' domain are defined as having at least a 0.4 full-time equivalent (FTE) IBD nurse, a named clinical lead and an IBD helpline. This service is an alternative to the full IBD team defined in the Interim Australian IBD Standards 2015 which was so rare that it was not a suitable domain for analysis.

Table 8 Volume profile of IBD care (separations) by State, 1 December 2013 to 30 November 2014

IBD separations	Survey			State					
	Paediatric	Adult	Total	NSW/ ACT	QLD	SA	WA/TAS	VIC	Total
	n	n	N	n	n	n	n	n	N
1-49	1	25	26	8	6	2	2	8	26
50-99	4	16	20	8	4	3	1	4	20
100+	1	22	23	6	5	2	1	9	23
Total	**6**	**63**	**69**	**22**	**15**	**7**	**4**	**21**	**69**

Table 9 Volume of IBD care by Partial IBD Service and IBD nurse, 1 December 2013 to 30 November 2014

IBD separations	Partial IBD Service			IBD nurse		
	No	Yes	Total	No	Yes	Total
	n	n	N	n	n	N
1-49	25	1	26	19	3	22
50-99	15	5	20	12	8	20
100+	12	11	23	8	15	23
Total	**52**	**17**	**69**	**39**	**26**	**65**

Remoteness

Geographical categorisation or remoteness for each site is reported according to the Australian Standard Geographic Classification (ASGC) Remoteness Areas (Table 10). Remoteness is also reported for site IBD volume and IBD nurse presence (Table11).

Table 10 Remoteness of participating sites, 1 December 2013 to 30 November 2014

Remoteness area	Survey			State					
	Paediatric	Adult	Total	NSW/ ACT	QLD	SA	WA/TAS	VIC	Total
	n (%)	n (%)	N (%)	n (%)	n (%)	n (%)	n (%)	n (%)	N (%)
Major cities	6 (100)	45 (69)	51 (72)	20 (83)	10 (67)	5 (71)	2 (50)	14 (67)	51 (72)
Inner regional	0 (0)	13 (20)	13 (18)	3 (13)	3 (20)	0 (0)	2 (50)	5 (24)	13 (18)
Outer regional	0 (0)	7 (11)	7 (10)	1 (4)	2 (13)	2 (29)	0 (0)	2 (10)	7 (10)
Total	**6 (100)**	**65 (100)**	**71 (100)**	**24 (100)**	**15 (100)**	**7 (100)**	**4 (100)**	**21 (100)**	**71 (100)**

Table 11 Remoteness by site IBD volume and IBD nurse, 1 December 2013 to 30 November 2014

Remoteness area	IBD separation categories				IBD nurse		
	1-49	50-99	100+	Total	No	Yes	Total
	n (%)	n (%)	n (%)	N (%)	n (%)	n (%)	N (%)
Major cities	9 (18)	18 (37)	22 (45)	49 (100)	27 (53)	24 (47)	51 (100)
Inner regional	10 (77)	2 (15)	1 (8)	13 (100)	10 (91)	1 (9)	11 (100)
Outer regional	7 (100)	0 (0)	0 (0)	7 (100)	4 (80)	1 (20)	5 (100)
Total	**26 (38)**	**20 (29)**	**23 (33)**	**69 (100)**	**41 (61)**	**26 (39)**	**67 (100)**

All sites with a Partial IBD Service were located in 'Major cities'.

Hospital activity (Organisational Audit)

Participating sites reported their total IBD overnight admissions (acute separations) for the audit year December 2013 to November 2014 (Table 12). This is 59% of the national total of overnight admissions for principal or additional diagnoses of Crohn's disease or ulcerative colitis.

Table 12 Crohn's disease and ulcerative colitis separations for the audit year, 1 December 2013 to 30 November 2014

Seperations Descriptions	Total	Survey		Partial IBD Service	IBD nurse
		Paediatric	Adult		
	Total (%)	Total (%)	Total (%)	Total (%)	Total (%)
Crohn's disease overnight	3246	283	2963	1297 (40)	1767 (55)
Ulcerative colitis overnight	2040	145	1895	798 (39)	1079 (54)
IBD overnight separations	5286	428	4858	2095 (40)	2846 (55)
Crohn's disease overnight < 18 years	394 (12)	263 (93)	131 (4)	114 (9)	270 (15)
Ulcerative colitis overnight seperations < 18 years	203 (10)	137 (94)	66 (3)	74 (9)	133 (12)
IBD overnight separations < 18 years	597 (11)	400 (93)	197 (4)	188 (9)	403 (14)

IBD: inflammatory bowel disease

All separations reported in the Organisational Audit should relate to principal diagnosis of Crohn's disease or ulcerative colitis. However data analysis noted that some sites had reported separations with additional diagnoses of Crohn's disease or ulcerative colitis. All separations-related results should be interpreted with this in mind.

The median number of admissions for a site (audit year) for Crohn's disease was 43 at adult sites and 38 at paediatric sites. For ulcerative colitis it was 26 and 22.

The median length of stay (interquartile range) for individual sites was 6 (5-8) days for Crohn's disease and 7 (5-9) days for those with ulcerative colitis.

About the Crohn's disease admissions

Over 70% of Crohn's disease admissions were unplanned and a further 10% were unplanned readmissions within 30 days. Only 15% were admissions for elective surgical procedures.

About the ulcerative colitis admissions

Similarly, 70% of ulcerative colitis admissions were unplanned and a further 12% were unplanned readmissions within 30 days. A similar proportion of patients (16%) to that for patients with Crohn's disease were admitted for elective surgical procedures.

IBD patients managed by sites

Sites were asked to report the number of patients they manage; they were permitted to use estimates if database figures were not available (Table 13).

Table 13 Number of IBD patients managed by participating sites, 1 December 2013 to 30 November 2014

IBD patients	N	Total	Survey		Separations categories			Partial IBD Service		IBD nurse	
			Paediatric	Adult	1-49	50-99	100+	No	Yes	No	Yes
		median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)
How many IBD patients did your service manage for the specified time period?	63	250 (100,800)	208 (158, 270)	300 (90, 850)	50 (14, 190)	218 (150, 350)	1000 (400, 1115)	158 (50, 400)	886 (450, 1115)	150 (50, 300)	650 (325, 1000)
Only 29% of sites obtained data from a database/register											
How many IBD patients were seen in outpatients?	62	208 (45, 500)	198 (158, 270)	226 (40, 547)	26 (1, 140)	159 (88, 283)	612 (350, 900)	108 (25, 350)	650 (300, 867)	78 (13, 250)	434 (265, 798)
Only 15% obtained data from a database/register											
How many new IBD patients has your centre seen for the specified period?	62	40 (20, 73)	33 (27, 42)	45 (20, 81)	20 (2, 33)	38 (23, 50)	90 (50, 133)	35 (18, 50)	105 (42, 133)	25 (11, 50)	77 (40, 120)
Only 23% obtained data from a database/register											

Q1: Interquartile range quartile 1

Q3: Interquartile range quartile 3

Measuring IBD services against the Interim IBD Standards 2015 –Organisational and Clinical Audit

The following information reports a selection of data concerning resources, organisation and quality of care according to the Interim Australian IBD Standards 2015 collected in the Organisational Audit and Clinical Audit. Full data are provided in Section 3.

There was room for improvement at all sites in almost all aspects of the Interim IBD Standards 2015 as is apparent in the following overview of performance. The results in most cases do not need qualification. However, comments have been made where the Committee feels there is a pressing need for improvements in performance, particularly when such improvements are likely to lead to significant benefits to patients and healthcare systems.

Sites with a Partial IBD Service were more likely to have:

- a multidisciplinary team
- appropriate investigation and management particularly with the use of immunosuppressive and biological medications
- higher levels of safety monitoring of immunosuppressive and biological medications
- access to specialised surgery and its perioperative management
- better documentation in the clinical record
- consistently provided patient education materials and advice.

Although this audit was directed more towards process, there were significant benefits in outcomes when sites with a Partial IBD Service were compared to those without. The most important benefit is a 15% reduction in the rate of emergency admissions. Other Australian studies provide supportive evidence that the presence of a helpline and the availability of a specialised IBD nurse are major drivers of a reduction in emergency admissions and IBD-related healthcare costs.[14]

Standard A - High-quality clinical care

Standard A1 - The IBD team

Only one site had a full IBD team as defined in the Interim Australian IBD Standards 2015; 24% had a Partial IBD Service as described above, and 39%, an IBD nurse. Of the participating sites, 80% had a gastroenterologist; 67%, an IBD-focused gastroenterologist; 64%, a colorectal surgeon; 52%, a dietitian; 88%, a stoma nurse; 4%, dedicated psychological service; and 22%, a dedicated pharmacist. A named clinical lead for IBD was reported in 43% of sites.

The Committee recognises that it is not possible for all sites to provide the full complement of staff that would enable sites to offer the range of services that are required by people with IBD. However all major city teaching hospitals and every site caring for a population of greater than 250 000 should have the IBD team resources described in the Standards.

Standard A2 - Essential supporting services

Access to allied professionals with an interest in IBD was variable: rheumatologist (42%); radiologist (40%), histopathologist (43%). Only three sites had a mental-health clinician within their service. Of all participating sites, 11% of Crohn's disease and ulcerative colitis separations involved provision of psychological care by any profession, most commonly social workers.

Standard A3 - Multidisciplinary working

A3.1 - IBD team meetings

Multidisciplinary meetings to discuss complex cases were reported as available at 43% of sites but were more common at sites with a Partial IBD Service (88%) or IBD nurse (81%). Pharmacists were rarely involved at any site (17%).

Only 13% of Crohn's disease and 10% of ulcerative colitis separations involved a multidisciplinary meeting. In certain subspecialties, for example, cancer care[15] and chronic disease,[16] multidisciplinary care improves patient outcomes. Although not yet shown for IBD, given the complexity and chronicity of the associated medical problems, it would seem reasonable to make that assumption. This facet of care is addressed in NICE IBD quality statement 2.[9]

Standard A3.2 - Medical/surgical interaction

Joint or parallel outpatient medical and surgical clinics occurred at 24% of all sites, and 59% of sites with a Partial IBD Service. See Standard A3.1 and NICE IBD quality statement 3.[9]

Standard A4 - Referral of suspected IBD patients

Of all participating sites, 86% reported seeing urgent referrals within 4 weeks (94% vs 86% for those with and without a Partial IBD Service). Urgent referral pathways between general practitioners (GPs) and outpatient clinics were less common (52%). Failure to arrange an early assessment and treatment of acutely unwell patients may lead to adverse outcomes. See also NICE IBD quality statement 1[9].

Standard A5 - Access to nutritional support and therapy

There was access to publically funded dietitians at 63% of sites. Nutritional risk screening was documented in 40% of Crohn's disease and 38% ulcerative colitis admissions. Nutritional screening was less common for paediatric admissions (19%; 13%). Dietetic assessment was completed in 46% of both Crohn's disease and ulcerative colitis admissions.

In 18% of Crohn's disease and 16% of ulcerative colitis admissions, patients were malnourished. Among the Crohn's disease admissions for people under 18 years of age malnutrition was recorded in 35% of cases. Malnutrition is a major and consistent predictor of increased surgical complications, prolonged length of stay and emergency readmission in people with IBD. Involvement of a dietitian pre and postoperatively improves outcomes.

Standard A6 - Arrangements for the use of immunomodulator and biological therapies

Most sites (88%) provided estimates rather than database figures on their use of immunomodulatory and biological therapies. For Crohn's disease, biological agents (infliximab and adalimumab) were used in 25% of patients and immunosuppressive medications (azathioprine, mercaptopurine or methotrexate) in 70%. For ulcerative colitis the figures were 3% and 40% (biological agents were not listed on the Pharmaceutical Benefits Scheme (PBS) for ulcerative colitis during the period of the audit). Sites with a Partial IBD Service had double the number of patients on biological agents than sites without (31% vs 15%), but had similar proportions of patients on immunosuppressive medications (73% and 68%, respectively).

Most sites had vaccination programs (93%) and counselling about risk of malignancy and sepsis (96%). Sites with an IBD nurse performed appreciably better in terms of established protocols and guidelines for patient management: 92% vs 66% for protocols for appropriate screening before administration of anti-TNF biological medications. Of sites with a nurse versus sites without, 65% vs 15% had protocols available to guide staff if white cell counts were low. Overall, 31% had shared-care arrangements for prescribing and monitoring immunosuppressive drugs.

A plan for safety monitoring for biological agents in Crohn's disease was implemented in 92% of Partial IBD Services compared to 53% of sites without a Partial IBD Service; for immunosuppressive drugs, 83% vs 54% respectively. See also NICE IBD quality statement 4.[9]

Standard A7 - Surgery for IBD

Surgery for IBD can be very specialised particularly where there is a need for repeat operative interventions. Moreover, certain complex operations, such as ileal pouch anal anastomosis (IPAA or pouch surgery), should be done only in centres where there is a high volume of cases, experienced surgeons and a multidisciplinary approach. Outcomes for colorectal surgery are likely to be improved at surgical sites using the full range of open, laparoscopic and minimally invasive techniques.

There were 261 surgical procedures performed in 168 (22%) of the admissions for people with Crohn's disease. One hundred and eighty nine were abdominal procedures and 27 involved the fashioning of a stoma. There was a documented pre-operative review by a stoma therapist in 29% of those who had a stoma fashioned. Failure of medical therapy was an indication for surgery in 22% of cases. Surgery was performed laparoscopically (or laparoscopic assisted) in 48% of cases. Postoperative complications occurred in 32% of patients, mainly infections and postoperative ileus.

There were 195 surgical procedures performed in 107 (16%) of the admissions for people with ulcerative colitis. One hundred and sixty were abdominal procedures and 49 involved the fashioning of a stoma. There was a documented preoperative review by a stomal therapist in 71% of those who had a stoma fashioned. Failure of medical therapy was an indication for surgery in 46% of cases. Surgery was performed laparoscopically (or laparoscopic assisted) in 46% of cases. Postoperative complications occurred in 40% of patients, mainly infections and postoperative ileus.

Only 51% of sites responded that complex surgical procedures were undertaken following joint discussion between medical, surgical and other multidisciplinary team members: this occurred in 94% of sites with and only 36% of sites without a Partial IBD Service. (See NICE IBD quality statement 3)[6]. A review of individual patients showed that there was documentation of multidisciplinary team meeting review in only 13% of non-elective patients with Crohn's disease and 10% of those with ulcerative colitis. Of participating sites, 79% had formal, regular governance processes to review surgical morbidity and mortality.

Laparoscopic-assisted surgery was available in all sites with and 80% of sites without a Partial IBD Service. Nearly 90% of sites with and 53% of sites without a Partial IBD Service performed complex IBD surgery on site.

Standard A8 - Inpatient facilities

Most high-volume sites had appropriate intensive care and high dependency wards or both, and colocation of medical gastroenterology and surgical colorectal facilities. Low-volume sites often lacked these facilities. Identifiable gastroenterology wards were only available at 52% of sites overall. A similar number had the recommended ratio of one toilet to three beds, and 88% had suitable privacy and ventilation in the toilets.

Only 62% of Crohn's disease and 64% of ulcerative colitis admissions were managed in a specialist gastroenterology ward.

Standard A9 - Access to diagnostic services

Onsite access to diagnostic imaging within 24 hours was high, but there was variability in the modalities available: computed tomography (CT) scanning was available at 99% of sites; ultrasonography at 85%; and magnetic resonance imaging (MRI) scanning at only 57%. The preferred imaging modalities for investigation in people with IBD is an ultrasound or an MRI because of the risks of radiation exposure when repeated investigations are required, particularly in young people. There was access to urgent endoscopy (within 72 hours) for patients with relapse at 94% of sites.

Abdominal X-ray was the most common type of imaging used in around half of patients admitted. Abdominal CT was used in 40% of adult Crohn's disease admissions but in just 13% of admissions for people under 18 years of age. Overall it was used in 19% of ulcerative colitis admissions.

Standard A10 - Inpatient care

The patient audit highlighted many areas in which improvements in process and documentation were possible. For example, policies or protocols for the management of suspected new IBD presentations, flares of ulcerative colitis, flares of Crohn's disease or presentations with acute severe ulcerative colitis were available at less than 28% of sites. Formal, validated symptom scores and the results of investigations were

generally poorly documented in the records with important gaps in clinical information, test results and management plans.

Formal nutritional risk assessment was completed for 40% of Crohn's disease and 38% of ulcerative colitis admissions, with lower rates for those under 18 years of age.

There were 77% of Crohn's disease admissions under the care of a gastroenterology unit. A visit by the specialist IBD nurse was reported in 16% of Crohn's disease and 18% of ulcerative colitis admissions. This result is likely to reflect an absence of IBD nurses at more than half the sites and the predominantly outpatient-service workload of IBD nurses.

Standard A11 - Outpatient care

Of the participating sites, 73% had a gastroenterology clinic, 51% had a specific IBD clinic and 51% ensured surveillance colonoscopy was offered.

Around 70% of audited patients had outpatient or private practice visits in the previous 12 months and nearly half had active disease at the previous visit. The median number of outpatient visits in the previous 12 months was three.

Standard A12 - Arrangements for the care of children and young people who have IBD

All the participating paediatric specialist hospitals had a paediatric gastroenterologist and paediatric anaesthetist while only half had a paediatric colorectal surgeon. Adult (general) hospitals that provided services to people under 18 years of age were less likely to have these positions, age-appropriate facilities or transitional care services. Please see also NICE IBD quality statement 2.[9]

Of those under 18 years of age admitted on a treatment for Crohn's disease, 14% were on exclusive enteral nutrition and 28% were commenced on exclusive enteral nutrition as a treatment, which approaches the number commenced on corticosteroids (35%).

Paediatric surgery rates were similar to those for adults but were more commonly for abscess drainage (50% of Crohn's disease procedures).

Standard B Local delivery of care

Standard B1 - Arrangements for shared care

Communication between hospitals for referral, or specialised advice for complex patients occurred generally by telephone, email or letter. A limited number of sites used videoconferencing or telehealth consultations. Communication with GPs about the need for annual review of specific risks was lacking: colorectal cancer surveillance (56%), assessment of renal function (24%) and bone densitometry (32%).

Of all patient admissions, 95% had a documented plan for follow up and 82% had a discharge summary sent by post, faxed or emailed to their GP.

Standard C Maintaining a patient-centred service

Standard C1 - Information on the IBD service

Of the participating sites, 63% provided written information on accessing IBD services (96% at sites with an IBD nurse). Only 37% provided clear guidance on how to seek a second opinion.

Standard C2 - Rapid access to specialist advice

Comparing sites with an IBD nurse and those without, 92% with an IBD nurse had a helpline and 29% without an IBD nurse. Specialist face-to-face review within a week for relapsed patients could not be provided in 34% of participating sites.

Standard C3 - Supporting patients to exercise choice between treatments

Involvement of the patient in decisions about care was actively encouraged in 64% of adult sites and all paediatric sites. There are no data to measure aspects of patient choice and involvement in care available through the patient file audit. These aspects would be better measured through direct survey of the experience of people with IBD.

Standard C4 - Supporting patients to exercise choice between different follow-up care models

Most sites offered the choice of annual review at a hospital clinic (69%) but less commonly in primary care (22%) and via telephone clinic (16%).

Standard C5 - Involvement of patients in service improvement

Half the sites offered an opportunity for patients to provide feedback on their care, but IBD-specific patient satisfaction surveys (20%) and IBD patient panels (3%) were infrequent.

Standard D Patient education and support

Standard D1 - Provision of Information

Provision of information material was more common at sites with an IBD nurse than without: IBD pregnancy and fertility information (77%; 46%), information material for newly diagnosed patients (96%; 64%) and information material on IBD treatments (96%; 51%).

Standard D2 - Education for patients

Patient education sessions for newly diagnosed patients were available at 85% of sites with an IBD nurse and 5% at sites without.

Standard D3 - Patient-support groups

Of the participating sites, 37% provided information to patients about organised local support groups.

Standard E Data, information technology and audit

Standard E1 - Register of patients under the care of the IBD service.

Of sites with a Partial IBD Service, 82% had a searchable database of IBD patients compared to 25% of those without the service.

Standard E2 Using IBD electronic clinical management system

Of the 82% of sites with a database, 88% recorded biological therapy, 62% recorded clinical inpatient data and 50% regularly recorded all immunosuppressive treatments prescribed. Only sites with a searchable database are equipped to undertake regular and reliable self-audit and practice review.

Standard E3 - Participation in audit

Audit of patients on both immunomodulatory and biological therapy was undertaken at 15% of participating sites and annual audit of IBD deaths was infrequently undertaken (38%).

Standard F Evidence-based practice and research

Standard F1 - Training and education

Opportunities for IBD-focused education for all medical and nursing staff was reported as being offered at 60% of sites.

Standard F2 - Research

Of 17 sites with a Partial IBD Service, 88% provided access to clinical trials while 31% of sites without a Partial IBD Service were able to provide this access. The availability of novel agents in clinical trials is an important aspect of service, particularly for patients who have not responded to standard therapies.

Standard F3 - Service development

Only 9% of sites conducted an annual review of their IBD service.

Section 3 Full result tables

Organisational audit data tables

Standard A High-quality clinical care

Standard A1 - The IBD team

The IBD team	Total		Survey		Separation category			
			Paediatric	Adult		1-49	50-99	100+
	N sites	Total, mean (% w FTE)	Total, mean (% w FTE)	Total, mean (% w FTE)	N Sites	Total, mean (% w FTE)	Total, mean (% w FTE)	Total, mean (% w FTE)
How many FTE gastroenterologists are there on site?	65	198, 3.0 (80)	21, 3.6 (100)	177, 3 (78)	63	19, 0.9 (48)	69, 3.5 (95)	104, 4.7 (95)
How many general paediatricians with an interest in gastroenterology on site?	6	0 (0)	0 (0)	0 (0)	6	0 (0)	0 (0)	0 (0)
How many gastroenterologists fractional 0.5 FTE or above?	67	186, 2.8 (73)	15, 2.5 (83)	171, 2.8 (72)	65	25, 1.1 (45)	70, 3.5 (90)	82, 3.6 (83)
How many FTE gastroenterologists have clinical focus on or responsibility for IBD?	67	84, 1.2 (67)	14, 2.4 (100)	69, 1.1 (64)	65	5, 0.2 (18)	33, 1.6 (90)	42, 1.8 (91)
How many FTE colorectal surgeons are there on site?	67	93, 1.4 (63)	5, 0.8 (50)	89, 1.5 (64)	65	10, 0.4 (32)	33, 1.6 (75)	43, 1.9 (78)
How many FTE IBD nurse specialists (excluding clinical trial nurses) on site?	67	27, 0.4 (39)	3, 0.5 (67)	24, 0.4 (36)	65	3, 0.1 (14)	5, 0.2 (40)	20, 0.9 (65)
How many FTE IBD nurse specialists have ongoing secure funding?	67	21, 0.3 (31)	2, 0.3 (33)	19, 0.3 (31)	65	3, 0.1 (14)	1, 0.1 (15)	17, 0.7 (65)
How many FTE clinical trial nurses are there on site?	67	27, 0.4 (34)	2, 0.4 (33)	25, 0.4 (34)	65	3, 0.1 (9)	4, 0.2 (25)	19, 0.8 (65)
How many FTE stoma nurses are there on site?	66	74, 1.1 (88)	6, 1 (100)	68, 1.1 (87)	64	16, 0.7 (82)	20, 1 (90)	36, 1.6 (95)
How many FTE dietitians are allocated to gastroenterology?	67	28, 0.4 (52)	5, 0.8 (100)	23, 0.4 (48)	65	3, 0.1 (18)	12, 0.6 (75)	10, 0.4 (65)
How many FTE administrators are attached to the IBD team?	67	7, 0.1 (19)	1, 0.2 (17)	6, 0.1 (20)	65	1, 0.1 (9)	2, 0.1 (15)	3, 0.1 (30)

Standard A1 - The IBD team (continued)

The IBD team cont.	Total		Partial IBD Service		IBD nurse		
			No	Yes		No	Yes
	N sites	Total, mean (% w FTE)	Total, mean (% w FTE)	Total, mean (% w FTE)	N Sites	Total, mean (% w FTE)	Total, mean (% w FTE)
How many FTE gastroenterologists are there on site?	65	198, 3.0 (80)	104, 2.2 (73)	94, 5.5 (100)	65	78, 2 (69)	120, 4.6 (96)
How many general paediatricians with an interest in gastroenterology on site?	6	0 (0)	0 (0)	0 (0)	6	0 (0)	0 (0)
How many gastroenterologists fractional 0.5 FTE or above?	67	186, 2.8 (73)	102, 2 (64)	84, 4.9 (100)	67	79, 1.9 (63)	107, 4.1 (88)
How many FTE gastroenterologists have clinical focus on or responsibility for IBD?	67	84, 1.2 (67)	52, 1 (56)	32, 1.9 (100)	67	36, 0.9 (51)	47, 1.8 (92)
How many FTE colorectal surgeons are there on site?	67	93, 1.4 (63)	59, 1.2 (56)	34, 2 (82)	67	45, 1.1 (49)	49, 1.9 (85)
How many FTE IBD nurse specialists (excluding clinical trial nurses) on site?	67	27, 0.4 (39)	9, 0.2 (18)	19, 1.1 (100)	67	0 (0)	27, 1 (100)
How many FTE IBD nurse specialists have ongoing secure funding?	67	21, 0.3 (31)	6, 0.1 (14)	15, 0.9 (82)	67	0 (0)	21, 0.8 (81)
How many FTE clinical trial nurses are there on site?	67	27, 0.4 (34)	10, 0.2 (22)	18, 1 (71)	67	8, 0.2 (17)	19, 0.7 (62)
How many FTE stoma nurses are there on site?	66	74, 1.1 (88)	46, 0.9 (84)	28, 1.7 (100)	66	34, 0.8 (80)	40, 1.5 (100)
How many FTE dietitians are allocated to gastroenterology?	67	28, 0.4 (52)	18, 0.4 (38)	10, 0.6 (94)	67	15, 0.4 (34)	13, 0.5 (81)
How many FTE administrators are attached to the IBD team?	67	7, 0.1 (19)	3, 0.1 (12)	4, 0.2 (41)	67	1, 0 (5)	5, 0.2 (42)

Standard A1 - The IBD team (continued)

IBD team cont.	Total	Survey		Separation category			Partial IBD Service		IBD nurse	
	n/N (%)	Paediatric n/N (%)	Adult n/N (%)	1-49 n/N (%)	50-99 n/N (%)	100+ n/N (%)	No n/N (%)	Yes n/N (%)	No n/N (%)	Yes n/N (%)
The IBD service has a named clinical lead	29/67 (43)	4/6 (67)	25/61 (41)	3/22 (14)	11/20 (55)	14/23 (61)	12/50 (24)	17/17 (100)	10/41 (24)	19/26 (73)
Partial IBD Service (derived)	17/71 (24)	2/6 (33)	15/65 (23)	1/26 (4)	5/20 (25)	11/23 (48)	0/0	17/17 (100)	0/41 (0)	17/26 (65)
IBD team (derived)	1/71 (1)	0/6 (0)	1/65 (2)	0/26 (0)	0/20 (0)	1/23 (4)	0/54 (0)	1/17 (6)	0/41 (0)	1/26 (4)
Gastroenterology team (derived)	27/71 (38)	3/6 (50)	24/65 (37)	3/26 (12)	11/20 (55)	12/23 (52)	14/54 (26)	13/17 (76)	9/41 (22)	18/26 (69)

FTE: full time employed
% w FTE: percentage with > 0 FTE

Standard A2 - Essential supporting services

Essential supporting services	Total	Survey		Separation category			Partial IBD Service	
		Paediatric	Adult	1-49	50-99	100+	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
There is a clear pathway for referring IBD patients to a rheumatologist	28/66 (42)	4/6 (67)	24/60 (40)	5/21 (24)	7/20 (35)	15/23 (65)	14/49 (29)	14/17 (82)
Radiologist with a special interest in gastroenterology supports IBD service	27/67 (40)	4/6 (67)	23/61 (38)	1/22 (5)	11/20 (55)	15/23 (65)	11/50 (22)	16/17 (94)
Named pharmacist with special interest in IBD or gastroenterology supports service	15/67 (22)	4/6 (67)	11/61 (18)	2/22 (9)	5/20 (25)	7/23 (30)	8/50 (16)	7/17 (41)
Access to a named ophthalmologist	8/67 (12)	3/6 (50)	5/61 (8)	3/22 (14)	4/20 (20)	1/23 (4)	5/50 (10)	3/17 (18)
Histopathologist with an interest in gastroenterology supports IBD service	29/67 (43)	6/6 (100)	23/61 (38)	4/22 (18)	13/20 (65)	11/23 (48)	15/50 (30)	14/17 (82)
The IBD Service includes a mental-health clinician	3/67 (4)	1/6 (17)	2/61 (3)	0/22 (0)	1/20 (5)	2/23 (9)	0/50 (0)	3/17 (18)
Paediatric patients with IBD can be referred to appropriate mental-health services. Paediatric only	6/6 (100)	6/6 (100)	0/0	1/1 (100)	4/4 (100)	1/1 (100)	4/4 (100)	2/2 (100)
Families and carers can be referred to appropriate mental-health services. Paediatric only	6/6 (100)	6/6 (100)	0/0	1/1 (100)	4/4 (100)	1/1 (100)	4/4 (100)	2/2 (100)
Counselling support information is available	38/67 (57)	6/6 (100)	32/61 (52)	7/22 (32)	13/20 (65)	16/23 (70)	25/50 (50)	13/17 (76)

Standard A3 Multidisciplinary working

Standard A 3.1 - IBD team meetings

IBD team meetings	Total	Survey		Partial IBD Service		IBD nurse	
		Paediatric	Adult	No	Yes	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Multidisciplinary meetings in which complex IBD cases can be discussed are held*	29/67 (43)	4/6 (67)	25/61 (41)	14/50 (28)	15/17 (88)	8/41 (20)	21/26 (81)
Multidisciplinary team decisions are documented in the patient notes	25/29 (86)	4/4 (100)	21/25 (84)	12/14 (86)	13/15 (87)	7/8 (88)	18/21 (86)
Gastroenterology dietitian - attendance at multidisciplinary team meetings. Always or sometimes	16/29 (55)	2/4 (50)	14/25 (56)	4/14 (29)	12/15 (80)	2/8 (25)	14/21 (67)
Pharmacist - attendance at multidisciplinary team meetings. Always or sometimes	5/29 (17)	1/4 (25)	4/25 (16)	1/14 (7)	4/15 (27)	1/8 (13)	4/21 (19)
Administrator - attendance at multidisciplinary team meetings. Always or sometimes	7/29 (24)	0/4 (0)	7/25 (28)	3/14 (21)	4/15 (27)	2/8 (25)	5/21 (24)

* Multidisciplinary meetings were most commonly held fortnightly with some held weekly or every 4 weeks

Standard A 3.2 - Medical/surgical interaction

Medical/surgical interaction	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Joint or parallel outpatient clinics for patients requiring this	16/66 (24)*	1/6 (17)	15/60 (25)	6/49 (12)	10/17 (59)

* In most cases the joint or parallel clinics occurred weekly

Standard A4 - Referral of suspected IBD patients

Referral of suspected IBD patients	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Suspected IBD patients referred to gastroenterology, IBD or surgical clinics	59/67 (88)	6/6 (100)	53/61 (87)	43/50 (86)	16/17 (94)
Agreed referral pathway for urgent outpatients between GPs and hospitals	35/67 (52)	6/6 (100)	29/61 (48)	22/50 (44)	13/17 (76)
Urgent referrals seen within 4 weeks or more rapidly if clinically necessary	57/66 (86)	6/6 (100)	51/60 (85)	41/49 (84)	16/17 (94)
GP guidance developed to help GPs identify and refer symptomatic patients	21/66 (32)	2/6 (33)	19/60 (32)	13/49 (27)	8/17 (47)

Standard A5 - Access to nutritional support and therapy

Access to nutritional support and therapy	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
IBD patients can be referred to a dietitian experienced in the dietary management of IBD if required					
Private service	10/67 (15)	1/6 (17)	9/61 (15)	9/50 (18)	1/17 (6)
Public service	42/67 (63)	5/6 (83)	37/61 (61)	26/50 (52)	16/17 (94)
Enteral nutrition as a primary treatment available to patients with Crohn's disease	42/67 (63)	6/6 (100)	36/61 (59)	25/50 (50)	17/17 (100)
Information given to all new IBD patients includes nutritional advice	48/67 (72)	5/6 (83)	43/61 (70)	33/50 (66)	15/17 (88)
Regular assessment to ensure nutritional intake appropriate for normal growth. Paediatric only	4/6 (67)	4/6 (67)	0/0	2/4 (50)	2/2 (100)
Home enteral and parenteral nutrition provision and monitoring always available	38/67 (57)	5/6 (83)	33/61 (54)	23/50 (46)	15/17 (88)

Standard A6 - Arrangements for the use of immunomodulator and biological therapies

Percentage of patients using immunomodulator and biological therapy		Total	Survey		Partial IBD Service		IBD nurse		State				
			Paediatric	Adult	No	Yes	No	Yes	NSW/ ACT	QLD	SA	WA/TAS	VIC
	N sites	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)	median (Q1, Q3)
With Crohn's disease on infliximab	65	15 (5, 21)	33 (25, 40)	11 (5, 20)	10 (5, 20)	18 (11, 25)	10 (5, 20)	18 (10, 25)	15 (5, 20)	8 (1, 18)	18 (11, 26)	13 (5, 23)	15, (6, 25)
With ulcerative colitis on infliximab	65	3 (0, 5)	3 (1, 10)	3 (0, 5)	3 (0, 5)	3 (1, 5)	2 (0, 5)	4 (1, 5)	5 (3, 10)	1 (0, 4)	0 (0, 4)	10 (3, 15)	2, (0, 5)
With Crohn's disease on adalimumab	65	10 (4, 14)	6 (1, 10)	10 (5, 14)	5 (2, 10)	13 (10, 15)	5 (1, 10)	10 (7, 15)	10 (5, 15)	7 (0, 11)	5 (1, 10)	3 (0, 8)	10, (5, 15)
With Crohn's on Immunomodulator therapy	67	70 (40, 85)	73 (70, 90)	63 (40, 80)	68 (35, 85)	73 (50, 75)	60 (30, 80)	75 (58, 85)	63 (55, 75)	80 (40, 90)	48 (3, 85)	33 (25, 58)	70, (50, 90)
With ulcerative colitis on Immunomodulator therapy	67	40 (20, 55)	55 (50, 65)	33 (20, 50)	35 (20, 50)	44 (30, 60)	30 (15, 50)	50 (30, 60)	40 (26, 50)	50 (30, 60)	21 (0, 30)	18 (5, 38)	50, (25, 55)
With IBD-unspecified on Immunomodulator therapy	67	15 (0, 50)	60 (50, 75)	10 (0, 40)	8 (0, 40)	40 (1, 55)	10 (0, 30)	32 (0, 50)	6 (0, 40)	25 (0, 50)	0 (0, 1)	0 (0, 5)	50, (10, 55)

Overall only 12% of participating sites collected the above data from a database or registry

Standard A6 - Arrangements for the use of immunomodulator and biological therapies (continued)

Arrangements for the use of immunomodulator and biological therapies	Total	Survey		IBD nurse	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Policy/protocol for screening for tuberculosis, hepatitis B and other relevant infections	51/67 (76)	5/6 (83)	46/61 (75)	27/41 (66)	24/26 (92)
Vaccination program for infections such as hepatitis B and varicella zoster considered	62/67 (93)	6/6 (100)	56/61 (92)	37/41 (90)	25/26 (96)
Immunosuppressive therapy counselling provided about risk of malignancy and sepsis	64/67 (96)	6/6 (100)	58/61 (95)	38/41 (93)	26/26 (100)
Local protocols for the administration of biological therapies	61/67 (91)	6/6 (100)	55/61 (90)	37/41 (90)	24/26 (92)
Process to have white blood count measured 3 monthly if on immunosuppressive therapy	50/67 (75)	5/6 (83)	45/61 (74)	26/41 (63)	24/26 (92)
Clinicians have access to a pharmacist with specialist knowledge or interest	26/67 (39)	4/6 (67)	22/61 (36)	11/41 (27)	15/26 (58)
Protocols for biotherapies include infusion reactions and accelerated infusions	57/67 (85)	6/6 (100)	51/61 (84)	33/41 (80)	24/26 (92)
Protocol available to guide staff in special circumstances (e.g. low white cell counts)	23/66 (35)	2/6 (33)	21/60 (35)	6/40 (15)	17/26 (65)
Patients on immunosuppressive therapy choose monitoring by hospital or in community	32/67 (48)	4/6 (67)	28/61 (46)	18/41 (44)	14/26 (54)
Patients receiving biological therapy reviewed at least 3 monthly	41/66 (62)	5/6 (83)	36/60 (60)	20/40 (50)	21/26 (81)
Local patient adverse events information sheet for all on immunosuppressive and biological therapy	34/66 (52)	4/6 (67)	30/60 (50)	15/40 (38)	19/26 (73)
Shared-care arrangements for monitoring and prescribing of immunosuppressive therapy	21/67 (31)	3/6 (50)	18/61 (30)	12/41 (29)	9/26 (35)

Standard A7 - Surgery for IBD

Surgery for IBD	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Surgeons perform ileoanal pouch surgery on site	41/66 (62)	5/6 (83)	36/60 (60)	26/49 (53)	15/17 (88)
Ileoanal pouch surgery by paediatric surgeon with an adult colorectal surgeon. Paediatric only	3/6 (50)	3/6 (50)		3/4 (75)	0/2 (0)
Formal regular governance process to review surgical morbidity and mortality	53/67 (79)	6/6 (100)	47/61 (77)	37/50 (74)	16/17 (94)
Facilities and trained surgeons to offer laparoscopic or laparoscopic-assisted surgery	57/67 (85)	6/6 (100)	51/61 (84)	40/50 (80)	17/17 (100)
Pouch surgery patients referred for pathological assessment if diagnosis uncertain	50/67 (75)	6/6 (100)	44/61 (72)	34/50 (68)	16/17 (94)
One consultant surgeon with dedicated IBD experience is the nominated lead	21/67 (31)	3/6 (50)	18/61 (30)	12/50 (24)	9/17 (53)
Pouch failure and salvage are managed in or referred to a regional specialist unit	36/67 (54)	5/6 (83)	31/61 (51)	23/50 (46)	13/17 (76)
Joint discussion by multidisciplinary team before complex surgical procedures	34/67 (51)	5/6 (83)	29/61 (48)	18/50 (36)	16/17 (94)
Annual review of activity, mortality and morbidity	10/67 (15)	0/6 (0)	10/61 (16)	5/50 (10)	5/17 (29)

Crohn's disease common surgical procedures Particpating sites, 1 December 2013 to 30 November 2014	Total	Survey	
		Paediatric	Adult
		Total	Total
Total proctocolectomy	2	0	2
Rectosigmoidectomy, Excision large intestine with formation of stoma	13	0	13
Abdominoperineal proctectomy	10	0	10
High anterior resection of rectum. Low or ultra low anterior resection of rectum	4	0	4
Perineal proctectomy	5	0	5
Left hemicolectomy with anastomosis. Excision large intestine with anastomosis	35	1	34
Right hemicolectomy with anastomosis. Extended right hemicolectomy with anastomosis	62	1	61
Right hemicolectomy with formation of stoma. Extended right hemicolectomy with formation of stoma	15	1	14
Total colectomy with ileostomy	19	0	19
Total colectomy with ileorectal anastomosis	4	0	4
Strictureplasty of small intestine	11	1	10
Resection of small intestine with formation of stoma	18	1	17
Resection of small intestine with anastomosis	55	0	55

Ulcerative colitis common surgical procedures Particpating sites, 1 December 2013 to 30 November 2014	Total	Survey	
		Paediatric	Adult
		Total	Total
Restorative proctectomy	32	6	26
Total proctocolectomy with ileoanal anastomosis	25	0	25
Rectosigmoidectomy with formation of stoma. Limited excision of large intestine with formation of stoma. Right hemicolectomy with formation of stoma. Extended right hemicolectomy with formation of stoma	18	1	17
Abdominoperineal proctectomy	7	0	7
High anterior resection of rectum. Low or ultra low anterior resection of rectum	3	0	3
Perineal proctectomy	2	0	2
Left hemicolectomy with anastomosis. Limited excision of large intestine with anastomosis. Right hemicolectomy with anastomosis. Extended right hemicolectomy with anastomosis	12	0	12
Total colectomy with ileostomy	60	2	58
Total colectomy with ileorectal anastomosis	5	1	4
Resection of small intestine with formation of stoma	1	0	1
Resection of small intestine with anastomosis	5	0	5

Standard A8 - Inpatient facilities

Inpatient facilities	Total	Survey		Separation category		
		Paediatric	Adult	1-49	50-99	100+
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
There is an identifiable gastroenterology ward	35/67 (52)	2/6 (33)	33/61 (54)	2/22 (9)	12/20 (60)	20/23 (87)
Intensive care unit (ICU) and mixed medical or surgical high dependency unit (HDU)	56/67 (84)	5/6 (83)	51/61 (84)	14/22 (64)	19/20 (95)	22/23 (96)
On the main ward there is at least one toilet per three beds	34/67 (51)	4/6 (67)	30/61 (49)	9/22 (41)	12/20 (60)	12/23 (52)
Gastroenterology and colorectal surgical facilities are on the same site	49/67 (73)	6/6 (100)	43/61 (70)	11/22 (50)	17/20 (85)	20/23 (87)
IBD or suspected IBD patients are triaged to gastroenterology ward on admission	32/35 (91)	2/2 (100)	30/33 (91)	2/2 (100)	10/12 (83)	19/20 (95)
Toilets have floor to ceiling partitions, full height doors and good ventilation	59/67 (88)	6/6 (100)	53/61 (87)	16/22 (73)	20/20 (100)	21/23 (91)

Standard A9 - Access to diagnostic services

Access to diagnostic services		Total	Survey	
			Paediatric	Adult
		n/N (%)	n/N (%)	n/N (%)
Gastrointestinal pathologist assessment is available before surgery	No	13/67 (19)	0/6 (0)	13/61 (21)
	Yes	36/67 (54)	6/6 (100)	30/61 (49)
	Uncertain	18/67 (27)	0/6 (0)	18/61 (30)
Inpatients have access to on-site ultrasound within 24 hours where required		57/67 (85)	6/6 (100)	51/61 (84)
Inpatients have access to on-site CT within 24 hours where required		66/67 (99)	6/6 (100)	60/61 (98)
Inpatients have access to on-site MRI within 24 hours where required		38/67 (57)	4/6 (67)	34/61 (56)
Abdominal X-ray on admission is routine practice if acute severe ulcerative colitis		56/67 (84)	4/6 (67)	52/61 (85)
X-ray reports of presence of toxic megacolon are documented	Paediatric only	4/6 (67)	4/6 (67)	
Paediatric patients undergo endoscopy in an age-appropriate environment	Paediatric only	6/6 (100)	6/6 (100)	
Urgent access to endoscopy - if admitted with relapse, can be scoped within 72 hours		63/67 (94)	6/6 (100)	57/61 (93)
All histological reports are available within 5 working days		61/66 (92)	5/6 (83)	56/60 (93)
Urgent histology biopsies can be reported within 2 days		56/66 (85)	6/6 (100)	50/60 (83)
Drainage of an abscess can be carried out by interventional radiology		51/66 (77)	4/6 (67)	47/60 (78)
Outpatient access to ultrasound, CT, MRI and endoscopic assessment within 4 weeks		51/67 (76)	3/6 (50)	48/61 (79)
Small bowel MRI is available as an alternative to CT scans		60/67 (90)	6/6 (100)	54/61 (89)
Consultant radiologist who primarily reports all gastrointestinal radiology		24/67 (36)	5/6 (83)	19/61 (31)
Histology reporting times and outpatient waiting times are audited		13/67 (19)	1/6 (17)	12/61 (20)
PUCAI score used at day 3 and 5 for assessment of patients with acute severe ulcerative colitis	Paediatric only	6/6 (100)	6/6 (100)	

PUCAI: Paediatric Ulcerative Colitis Activity Index

Standard A10 - Inpatient care

Inpatient care	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
The site has a policy or protocol that IBD patients have weight and nutritional risk assessment on admission	20/67 (30)	1/6 (17)	19/61 (31)	10/50 (20)	10/17 (59)
The site has a policy or protocol that IBD patients with diarrhoea have stool sample sent for stool culture on admission	38/67 (57)	4/6 (67)	34/61 (56)	22/50 (44)	16/17 (94)
The site has a policy or protocol that IBD patients have a stool chart recorded during hospitalisation	36/67 (54)	4/6 (67)	32/61 (52)	20/50 (40)	16/17 (94)
Policy or protocol for suspected new IBD presentation	10/67 (15)	4/6 (67)	6/61 (10)	5/50 (10)	5/17 (29)
Policy or protocol for flare of ulcerative colitis	13/67 (19)	3/6 (50)	10/61 (16)	6/50 (12)	7/17 (41)
Policy or protocol for flare of Crohn's disease	11/67 (16)	2/6 (33)	9/61 (15)	5/50 (10)	6/17 (35)
Policy or protocol for acute severe ulcerative colitis	19/67 (28)	3/6 (50)	16/61 (26)	8/50 (16)	11/17 (65)
Acute pain management team available on site	60/67 (90)	6/6 (100)	54/61 (89)	43/50 (86)	17/17 (100)
Pain scores routinely included in nursing observations for IBD patients	40/67 (60)	3/6 (50)	37/61 (61)	29/50 (58)	11/17 (65)
Inpatients have access to an IBD nurse during their admission	30/67 (45)	5/6 (83)	25/61 (41)	13/50 (26)	17/17 (100)
Usual practice to refer inpatient with severe pain to acute pain management team	46/60 (77)	6/6 (100)	40/54 (74)	34/43 (79)	12/17 (71)
There is access to a stoma nurse during hospitalisation	62/67 (93)	6/6 (100)	56/61 (92)	45/50 (90)	17/17 (100)
A named pharmacist is available to carry out inpatient drug reviews	14/67 (21)	3/6 (50)	11/61 (18)	8/50 (16)	6/17 (35)

Standard A11 - Outpatient care

Outpatient care	Total	Survey		Partial IBD Service	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Does your hospital have a gastroenterology clinic? Yes	49/67 (73)	6/6 (100)	43/61 (70)	32/50 (64)	17/17 (100)
Does your hospital have a specific IBD clinic? Yes	34/67 (51)	4/6 (67)	30/61 (49)	17/50 (34)	17/17 (100)
Clinic review documentation	48/67 (72)	5/6 (83)	43/61 (70)	33/50 (66)	15/17 (88)
Surveillance colonoscopy offered	34/67 (51)	2/6 (33)	32/61 (52)	23/50 (46)	11/17 (65)
Steroid usage is recorded	32/67 (48)	2/6 (33)	30/61 (49)	20/50 (40)	12/17 (71)
All children who have had ulcerative colitis for more than 8 years have a surveillance plan made and shared	2/6 (33)	2/6 (33)	0/0	1/4 (25)	1/2 (50)
Bone densitometry is offered if corticosteroids used for more than 3 months	38/67 (57)	2/6 (33)	36/61 (59)	29/50 (58)	9/17 (53)
Annual data is collected and presented on patients on steroids	4/67 (6)	0/6 (0)	4/61 (7)	2/50 (4)	2/17 (12)

Standard A12 - Arrangements for the care of children and young people who have IBD

Arrangements for the care of children and young people who have IBD	Total	Survey	
		Paediatric	Adult
	n/N (%)	n/N (%)	n/N (%)
There is a defined access to a consultant paediatric gastroenterologist. Paediatric only	6/6 (100)	6/6 (100)	
Access to paediatric gastroenterologist or paediatrician with interest in gastroenterology. Adult only	10/61 (16)		10/61 (16)
Anaesthesia for IBD surgery carried out by accredited paediatric anaesthetist. Paediatric only	6/6 (100)	6/6 (100)	
Surgeon and anaesthetist with appropriate paediatric training. Adult only	17/31 (55)		17/31 (55)
Inpatients are looked after in an age-appropriate environment. Adult only	22/31 (71)		22/31 (71)
IBD nurse specialist with suitable paediatric experience. Adult only	5/31 (16)		5/31 (16)
Paediatric patients undergo endoscopy in an age-appropriate environment. Adult only	7/31 (23)		7/31 (23)
Dietitian with suitable paediatric experience. Adult only	10/31 (32)		10/31 (32)
Radiologist with suitable paediatric experience. Adult only	10/31 (32)		10/31 (32)
Transitional care service within the hospital to support young people	16/66 (24)	5/6 (83)	11/60 (18)
Each young person with IBD has an individual transition plan	15/66 (23)	3/6 (50)	12/60 (20)
Age-appropriate written and verbal advice is provided	26/66 (39)	6/6 (100)	20/60 (33)
Support and education is provided on sexual health in young people with IBD	27/66 (41)	6/6 (100)	21/60 (35)
The IBD service has a specific paediatric-to-adult transition policy	12/66 (18)	3/6 (50)	9/60 (15)
Staff can refer young people to appropriate mental-health services	43/66 (65)	6/6 (100)	37/60 (62)
There is a close working relationship with appropriate mental-health services	21/66 (32)	2/6 (33)	19/60 (32)
The IBD service has a joint transition clinic with paediatric services	4/66 (6)	2/6 (33)	2/60 (3)

61% of general or adult hospitals look after patients under the age of 18 years. Of the six specialist paediatric hospitals only one provided services to those 18-20 years.

63% of sites with a Partial IBD Service provided transitional care service within the hospital to support young people compared to 12% of sites without a Partial IBD Service.

Standard B Local delivery of care

Standard B1 - Arrangements for shared care

Arrangements for shared care	Total	Survey	
		Paediatric	Adult
	n/N (%)	n/N (%)	n/N (%)
GP instructed regarding assessment of need for colorectal cancer surveillance	38/68 (56)	2/6 (33)	36/62 (58)
GP instructed regarding assessment of need for renal function	16/68 (24)	2/6 (33)	14/62 (23)
GP instructed regarding assessment of need for bone densitometry	22/68 (32)	1/6 (17)	21/62 (34)
GP instructed regarding assessment of need for none of the above	26/68 (38)	4/6 (67)	22/62 (35)

Communication with another IBD service generally occurred for referral of a patient for ongoing care, or for advice from larger tertiary or specialised sites for more complex patients. Various means of communication were reported, with many being on an ad hoc basis. Telephone, email, post and fax were the most common methods of contact outlined. Limited services stated they were able to share the electronic and hard copy of medical records for easy access to patient histories. A limited number of sites reported communicating via videoconference and telehealth facilities. Few sites described more formal processes, particularly for transition patients or services within similar health networks, which involved attending shared meetings or medical record review.

Standard C Maintaining a patient-centred service

Standard C1 - Information on the IBD service

Information on the IBD service	Total	Survey		IBD nurse	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Written information provided re accessing IBD services, follow-up arrangements	41/65 (63)	5/6 (83)	36/59 (61)	16/39 (41)	25/26 (96)
There is clear guidance about how patients can seek a second opinion if they wish	24/65 (37)	3/6 (50)	21/59 (36)	12/39 (31)	12/26 (46)

Standard C2 - Rapid access to specialist advice

Rapid access to specialist advice	Total	Survey		Partial IBD Service		IBD nurse	
		Paediatric	Adult	No	Yes	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Written information for patients on whom to contact in the event of a relapse	43/65 (66)	5/6 (83)	38/59 (64)	26/48 (54)	17/17 (100)	17/39 (44)	26/26 (100)
Patients have access to contact an IBD specialist nurse or doctor by telephone	41/65 (63)	6/6 (100)	35/59 (59)	24/48 (50)	17/17 (100)	15/39 (38)	26/26 (100)
Email - patients and carers are able to contact an IBD specialist nurse or doctor	32/65 (49)	6/6 (100)	26/59 (44)	17/48 (35)	15/17 (88)	8/39 (21)	24/26 (92)
Patients who contact the service are answered within 48 hours	36/65 (55)	6/6 (100)	30/59 (51)	19/48 (40)	17/17 (100)	12/39 (31)	24/26 (92)
Specialist review (face-to-face) for relapsed patients is available. Within 7 days	42/64 (66)	6/6 (100)	36/58 (62)	29/47 (62)	13/17 (76)	23/38 (61)	19/26 (73)
8 to 14 days	16/64 (25)	0/6 (0)	16/58 (28)	12/47 (26)	4/17 (24)	10/38 (26)	6/26 (23)
15+ days	6/64 (9)	0/6 (0)	6/58 (10)	6/47 (13)	0/17 (0)	5/38 (13)	1/26 (4)
IBD helpline (derived)	36/71 (51)	6/6 (100)	30/65 (46)	19/54 (35)	17/17 (100)	12/41 (29)	24/26 (92)

The data item IBD helpline, is derived from responses to questions confirming patients have access to contact an IBD specialist nurse or doctor by telephone or email with a response within 48 hours.

Standard C3 - Supporting patients to exercise choice between treatments

Supporting patients to exercise choice between treatments	Total	Survey		Partial IBD Service		IBD nurse	
		Paediatric	Adult	No	Yes	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Patients are actively involved in management decisions about care	44/65 (68)	6/6 (100)	38/59 (64)	30/48 (63)	14/17 (82)	23/39 (59)	21/26 (81)

Standard C4 - Supporting patients to exercise choice between different follow-up care models

Supporting patients to exercise choice between different follow-up care models	Total	Survey	
		Paediatric	Adult
	n/N (%)	n/N (%)	n/N (%)
Patients offered choice of annual review - hospital clinic	47/68 (69)	6/6 (100)	41/62 (66)
Patients offered choice of annual review - telephone clinic	11/68 (16)	1/6 (17)	10/62 (16)
Patients offered choice of annual review - in primary care	15/68 (22)	0/6 (0)	15/62 (24)
Patients offered choice of annual review - none	14/68 (21)	0/6 (0)	14/62 (23)

Standard C5 - Involvement of patients in service improvement

Involvement of patients in service improvement	Total	Survey	
		Paediatric	Adult
	n/N (%)	n/N (%)	n/N (%)
IBD patients are given the opportunity to provide feedback on their care	33/65 (51)	4/6 (67)	29/59 (49)
At least one means of assessing patient satisfaction is used	13/65 (20)	0/6 (0)	13/59 (22)
Patients are involved in service planning and improvement	11/65 (17)	1/6 (17)	10/59 (17)
The service has IBD patient panel or similar patient involvement group	2/65 (3)	1/6 (17)	1/59 (2)
Reporting as a result of patients' feedback of their care within the last year	8/65 (12)	1/6 (17)	7/59 (12)

Standard D Patient education and support

Standard D1 - Provision of information

Provision of information	Total	Survey		IBD nurse	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Information about IBD in pregnancy and its effects on fertility is available	39/67 (58)	3/6 (50)	36/61 (59)	19/41 (46)	20/26 (77)
Patients and their partners are given advice on sexuality and body image	42/67 (63)	6/6 (100)	36/61 (59)	21/41 (51)	21/26 (81)
Agreed clinical pathway between women's health unit, adolescent gynaecology and IBD services	14/67 (21)	1/6 (17)	13/61 (21)	6/41 (15)	8/26 (31)
All newly diagnosed patients are given educational material routinely	50/65 (77)	6/6 (100)	44/59 (75)	25/39 (64)	25/26 (96)
Written information about IBD and a range of treatments is available to all patients	45/65 (69)	6/6 (100)	39/59 (66)	20/39 (51)	25/26 (96)
Written information provided to patients as part of the consultation	42/65 (65)	6/6 (100)	36/59 (61)	20/39 (51)	22/26 (85)
Access to a translator for all face-to-face and telephone contacts	38/65 (58)	5/6 (83)	33/59 (56)	21/39 (54)	17/26 (65)
Information is appropriate to age, understanding and communication needs of patients	40/65 (62)	6/6 (100)	34/59 (58)	21/39 (54)	19/26 (73)
Written information is available for patients in languages other than English	4/65 (6)	1/6 (17)	3/59 (5)	3/39 (8)	1/26 (4)
Stable patients given a clear plan about what to do in the event of a flare-up	52/65 (80)	3/6 (50)	49/59 (83)	32/39 (82)	20/26 (77)

Standard D2 - Education for patients

Education for patients	Total	Survey		IBD nurse	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
All newly diagnosed patients are offered a patient education session routinely	24/65 (37)	4/6 (67)	20/59 (34)	2/39 (5)	22/26 (85)
Regular education opportunities for all IBD patients and their families	14/65 (22)	4/6 (67)	10/59 (17)	1/39 (3)	13/26 (50)

Standard D3 - Patient support groups

Patient support groups	Total	Survey		IBD nurse	
		Paediatric	Adult	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Written information is made available to all new patients about relevant patient organisations	42/65 (65)	6/6 (100)	36/59 (61)	18/39 (46)	24/26 (92)
Information provided about their local patient support groups	24/65 (37)	5/6 (83)	19/59 (32)	9/39 (23)	15/26 (58)
IBD team circulate information about local support groups regularly e.g. CCA, pouch and ostomy support groups	31/65 (48)	6/6 (100)	25/59 (42)	13/39 (33)	18/26 (69)

Standard E Patient education and support

Standard E1 - Register of patients under the care of the IBD service

Standard E2 - Using an IBD electronic clinical management system

Register of patients under the care of the IBD service Using IBD electronic clinical management system	Total	Survey		Partial IBD Service		IBD nurse	
		Paediatric	Adult	No	Yes	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Searchable database or registry of adult and paediatric IBD patients	26/65 (40)	5/6 (83)	21/59 (36)	12/48 (25)	14/17 (82)	4/39 (10)	22/26 (85)
Database is updated with clinical data about IBD patients receiving hospital care	16/26 (62)	2/5 (40)	14/21 (67)	6/12 (50)	10/14 (71)	3/4 (75)	13/22 (59)
Database is updated with patients on biological therapy	23/26 (88)	3/5 (60)	20/21 (95)	10/12 (83)	13/14 (93)	2/4 (50)	21/22 (95)
Database is updated with patients on all immunosuppressive therapy	13/26 (50)	0/5 (0)	13/21 (62)	4/12 (33)	9/14 (64)	2/4 (50)	11/22 (50)
Database is updated with clinical data about all patients with a diagnosis of IBD	16/26 (62)	2/5 (40)	14/21 (67)	5/12 (42)	11/14 (79)	2/4 (50)	14/22 (64)

Standard E3 - Participation in audit

Participation in audit	Total	Partial IBD Service	
		No	Yes
	n/N (%)	n/N (%)	n/N (%)
IBD patients on both immunomodulator and biological therapy are regularly audited	10/66 (15)	5/49 (10)	5/17 (29)
All IBD inpatient deaths are reviewed by the IBD team at least annually	25/65 (38)	12/48 (25)	13/17 (76)
Multidisciplinary team meetings to discuss any deaths and outcomes of surgery	38/65 (58)	24/48 (50)	14/17 (82)

Standard F Evidence-based practice and research

Standard F1 - Training and education

Training and education	Total	Partial IBD Service	
		No	Yes
	n/N (%)	n/N (%)	n/N (%)
Education opportunities focused on IBD for all medical and nursing staff	39/65 (60)	23/48 (48)	16/17 (94)
The IBD team provides IBD training for GPs on an ad hoc basis	23/65 (35)	10/48 (21)	13/17 (76)

Standard F2 - Research

Research		Total	Survey		Partial IBD Service	
			Paediatric	Adult	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
The IBD service provides access to clinical trials		30/65 (46)	4/6 (67)	26/59 (44)	15/48 (31)	15/17 (88)
	N sites	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
How many patients were entered into a clinical trial for patients with Crohn's disease or ulcerative colitis in the last year?	30	3 (0, 10)	2 (0, 17)	4 (0, 10)	1 (0, 3)	10 (4, 19)
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Do you collaborate on clinical trials with other sites?		34/65 (52)	5/6 (83)	29/59 (49)	19/48 (40)	15/17 (88)
All members of service are encouraged to participate in research		18/65 (28)	2/6 (33)	16/59 (27)	7/48 (15)	11/17 (65)
If research encouraged, is this externally funded?		12/18 (67)	2/2 (100)	10/16 (63)	4/7 (57)	8/11 (73)

Standard F3 - Service development

Service development	Total	Partial IBD Service	
		No	Yes
	n/N (%)	n/N (%)	n/N (%)
An annual review of the IBD service is carried out	6/65 (9)	1/48 (2)	5/17 (29)
Annual review is attended by a multidisciplinary team	4/6 (67)	0/1 (0)	4/5 (80)
An annual action plan is completed as a result of the review	3/6 (50)	0/1 (0)	3/5 (60)

Clinical Audit data tables - Crohn's disease and ulcerative colitis

Data collected through the clinical audit of participating hospital separations from 1 December 2013 to 30 November 2014 are presented in this section. Data for separations with a principal diagnosis of Crohn's disease are presented first with ulcerative colitis data thereafter. All fields are shown for separations for people under 18 years of age, 18years of age and over and the total. Data are also presented for the 18 years and over cohort according to whether the separation occurred at a site with a Partial IBD Service or not.

Crohn's disease data tables

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
Site		Under 18	18 and over	All	No	Yes
		Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
Number of sites		N=22	N=45	N=50		
Cases per site		2 (1, 3)	15 (8, 24)	14 (9, 24)		
Demographics		**n/N (%)**	**n/N (%)**	**n/N (%)**	**n/N (%)**	**n/N (%)**
Age on admission (years)	0-8	3/75 (4)		3/767 (<1)		
	9-17	72/75 (96)		72/767 (9)		
	18-29		253/692 (37)	253/767 (33)	145/392 (37)	108/300 (36)
	30-39		149/692 (22)	149/767 (19)	74/392 (19)	75/300 (25)
	40-49		127/692 (18)	127/767 (17)	76/392 (19)	51/300 (17)
	50-59		89/692 (13)	89/767 (12)	46/392 (12)	43/300 (14)
	60-69		51/692 (7)	51/767 (7)	33/392 (8)	18/300 (6)
	70+		23/692 (3)	23/767 (3)	18/392 (5)	5/300 (2)
Gender	Female	33/75 (44)	386/692 (56)	419/767 (55)	216/392 (55)	170/300 (57)
	Male	42/75 (56)	304/692 (44)	346/767 (45)	176/392 (45)	128/300 (43)
	Other	0/75 (0)	2/692 (<1)	2/767 (<1)	0/392 (0)	2/300 (1)

Crohn's disease	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Admission / discharge		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
What was the primary reason for admission?	New diagnosis	22/75 (29)	81/692 (12)	103/767 (13)	47/392 (12)	34/300 (11)
	Emergency admission	34/75 (45)	430/692 (62)	464/767 (60)	270/392 (69)	160/300 (53)
	Planned admission (known case)	5/75 (7)	53/692 (8)	58/767 (8)	18/392 (5)	35/300 (12)
	Elective admission for surgery	7/75 (9)	70/692 (10)	77/767 (10)	29/392 (7)	41/300 (14)
	Transfer from another site	3/75 (4)	28/692 (4)	31/767 (4)	12/392 (3)	16/300 (5)
	Other	4/75 (5)	30/692 (4)	34/767 (4)	16/392 (4)	14/300 (5)
Source of admission						
Emergency department		45/75 (60)	475/692 (69)	520/767 (68)	298/392 (76)	177/300 (59)
Referred by GP		3/75 (4)	36/692 (5)	39/767 (5)	24/392 (6)	12/300 (4)
Advised to attend by IBD nurse helpline		2/75 (3)	14/692 (2)	16/767 (2)	0/392 (0)	14/300 (5)
Referred in from hospital outpatient department		11/75 (15)	79/692 (11)	90/767 (12)	25/392 (6)	54/300 (18)
Referred in from gastroenterologist rooms		3/75 (4)	51/692 (7)	54/767 (7)	27/392 (7)	24/300 (8)
Referred in from surgical specialist rooms		4/75 (5)	31/692 (4)	35/767 (5)	17/392 (4)	14/300 (5)
Transfer from another site		8/75 (11)	44/692 (6)	52/767 (7)	18/392 (5)	26/300 (9)
Other		6/75 (8)	25/692 (4)	31/767 (4)	13/392 (3)	12/300 (4)
Overnight admissions with Crohn's Disease in the two years prior to this admission at this hospital		34/75 (45)	316/692 (46)	350/767 (46)	168/392 (43)	148/300 (49)
		Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
Previous admissions: How many times in the two years before this admission?		N=33 2 (1, 3)	N=316 1 (1, 2)	N=349 1 (1, 3)	N=168 1 (1, 3)	N=148 1 (1, 2)
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Has there been a Crohn's disease-related admission within the last 30 days?	Yes	12/34 (35)	74/316 (23)	86/350 (25)	35/168 (21)	39/148 (26)
Where was the patient discharged to?	Home	72/75 (96)	656/692 (95)	728/767 (95)	367/392 (94)	289/300 (96)
	Own risk	0/75 (0)	18/692 (3)	18/767 (2)	12/392 (3)	6/300 (2)
	Nursing home/rehab	0/75 (0)	5/692 (1)	5/767 (1)	3/392 (1)	2/300 (1)
	Transfer - surgery	1/75 (1)	4/692 (1)	5/767 (1)	3/392 (1)	1/300 (<1)
	Transfer - medical management	2/75 (3)	8/692 (1)	10/767 (1)	6/392 (2)	2/300 (1)
	Deceased	0/75 (0)	1/692 (<1)	1/767 (<1)	1/392 (<1)	0/300 (0)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		Mean	Mean	Mean	Mean	Mean
Length of Stay (includes 1 Death, excludes 5 cases where admission date=discharge date)	days	6.7	7.6	7.5	6.8	8.7
		n (%)	n (%)	n (%)	n (%)	n (%)
1-2	days	9 (12)	145 (21)	154 (20)	91 (23)	54 (18)
3-6	days	38 (51)	310 (45)	348 (46)	169 (43)	141 (47)
7-13	days	20 (27)	173 (25)	193 (25)	100 (26)	73 (25)
14-27	days	6 (8)	37 (5)	43 (6)	19 (5)	18 (6)
28+	days	2 (3)	22 (3)	24 (3)	11 (3)	11 (4)
Was the death related to Crohn's disease?	Yes	0/0	1/1 (100)	1/1 (100)	1/1 (100)	0/0
Initial assessment during the first full day following admission		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was duration of disease stated in admission notes?	Yes. Excludes new diagnoses	33/53 (62)	440/611 (72)	473/664 (71)	246/345 (71)	194/266 (73)
Duration of disease (years), excludes new diagnoses	<1	5/33 (15)	46/440 (10)	51/473 (11)	24/246 (10)	22/194 (11)
	1-<2	8/33 (24)	46/440 (10)	54/473 (11)	26/246 (11)	20/194 (10)
	2-<5	11/33 (33)	91/440 (21)	102/473 (22)	54/246 (22)	37/194 (19)
	5-<10	8/33 (24)	95/440 (22)	103/473 (22)	46/246 (19)	49/194 (25)
	10+	1/33 (3)	162/440 (37)	163/473 (34)	96/246 (39)	66/194 (34)
		maximum= 10	maximum= 45	maximum= 45	maximum= 45	maximum= 33
Was the extent of the disease recorded in admission notes?	Yes. Excludes new diagnoses	25/53 (47)	387/611 (63)	412/664 (62)	192/345 (56)	195/266 (73)
What was the extent of disease recorded?	Excludes new diagnoses					
Terminal ileum		12/25 (48)	149/387 (39)	161/412 (39)	81/192 (42)	68/195 (35)
Colonic		7/25 (28)	99/387 (26)	106/412 (26)	45/192 (23)	54/195 (28)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Ileocolonic		11/25 (44)	155/387 (40)	166/412 (40)	74/192 (39)	81/195 (42)
Perianal		5/25 (20)	53/387 (14)	58/412 (14)	27/192 (14)	26/195 (13)
Upper gastrointestinal		5/25 (20)	17/387 (4)	22/412 (5)	8/192 (4)	9/195 (5)
Unknown		0/25 (0)	8/387 (2)	8/412 (2)	0/192 (0)	8/195 (4)
Was the number of liquid stools per day recorded in the clinical record?	Yes. Excludes 'Not applicable' and 'Stoma'	51/73 (70)	463/612 (76)	514/685 (75)	249/352 (71)	214/260 (82)
Was the presence of blood in the stools recorded in the clinical record?	Yes. Excludes 'Not applicable'	38/73 (52)	409/639 (64)	447/712 (63)	245/364 (67)	164/275 (60)
Was general wellbeing recorded in the clinical record?	Yes. Excludes 'Not applicable'	64/75 (85)	481/672 (72)	545/747 (73)	287/383 (75)	194/289 (67)
Was documentation of a perineal examination recorded in the clinical record?	Yes. Excludes 'Not applicable'	26/74 (35)	168/629 (27)	194/703 (28)	95/368 (26)	73/261 (28)
Were fevers recorded in the clinical record?	Yes	34/75 (45)	191/692 (28)	225/767 (29)	95/392 (24)	96/300 (32)
Was active perineal disease recorded in the clinical record?	Yes	13/75 (17)	82/692 (12)	95/767 (12)	38/392 (10)	44/300 (15)
Was abdominal mass recorded in the clinical record?	Yes	6/75 (8)	50/692 (7)	56/767 (7)	25/392 (6)	25/300 (8)
Was abdominal pain recorded in the clinical record?	Yes	63/75 (84)	554/692 (80)	617/767 (80)	332/392 (85)	222/300 (74)
Did the notes record current presence of:						
Mouth ulcers	Yes	13/75 (17)	25/692 (4)	38/767 (5)	9/392 (2)	16/300 (5)
Orofacial granulomatosis	Yes. Paediatric only	1/75 (1)		1/75 (1)		
Arthralgia	Yes	7/75 (9)	48/692 (7)	55/767 (7)	19/392 (5)	29/300 (10)
Arthritis	Yes	1/75 (1)	42/692 (6)	43/767 (6)	23/392 (6)	19/300 (6)
Ankylosing spondylitis	Yes	0/75 (0)	10/692 (1)	10/767 (1)	6/392 (2)	4/300 (1)
Erythema nodosum	Yes	1/75 (1)	7/692 (1)	8/767 (1)	4/392 (1)	3/300 (1)
Pyoderma gangrenosum	Yes	0/75 (0)	3/692 (<1)	3/767 (<1)	0/392 (0)	3/300 (1)
Iritis	Yes	0/75 (0)	3/692 (<1)	3/767 (<1)	1/392 (<1)	2/300 (1)
Anal fissure	Yes	7/75 (9)	22/692 (3)	29/767 (4)	13/392 (3)	9/300 (3)
Fistula	Yes	6/75 (8)	79/692 (11)	85/767 (11)	37/392 (9)	42/300 (14)
Abscess	Yes	10/75 (13)	58/692 (8)	68/767 (9)	25/392 (6)	33/300 (11)
Malnutrition	Yes	26/75 (35)	114/692 (16)	140/767 (18)	60/392 (15)	54/300 (18)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was a paediatric Crohn's disease activity index (PCDAI) score recorded?	Yes. Paediatric only	4/69 (6)		4/69 (6)		
Comorbidity						
Were any significant comorbid diseases documented?	Yes	27/75 (36)	319/692 (46)	346/767 (45)	184/392 (47)	135/300 (45)
	Statement that there were no relevant comorbidities	16/75 (21)	143/692 (21)	159/767 (21)	64/392 (16)	79/300 (26)
Which comorbidities were documented?						
Cardiovascular		4/27 (15)	59/319 (18)	63/346 (18)	33/184 (18)	26/135 (19)
Respiratory		7/27 (26)	57/319 (18)	64/346 (18)	32/184 (17)	25/135 (19)
Renal		0/27 (0)	18/319 (6)	18/346 (5)	14/184 (8)	4/135 (3)
Diabetes		1/27 (4)	14/319 (4)	15/346 (4)	7/184 (4)	7/135 (5)
Liver disease		0/27 (0)	11/319 (3)	11/346 (3)	8/184 (4)	3/135 (2)
Active cancer		0/27 (0)	8/319 (3)	8/346 (2)	5/184 (3)	3/135 (2)
Growth failure	Paediatric only	4/27 (15)		4/27 (15)		
Iron deficiency anaemia	Paediatric only	1/27 (4)		1/27 (4)		
Psychological condition		12/27 (44)	92/319 (29)	104/346 (30)	56/184 (30)	36/135 (27)
Other		9/27 (33)	183/319 (57)	192/346 (55)	105/184 (57)	78/135 (58)
Medication on admission						
Was the patient recorded as being on treatment for Crohn's disease on admission?	Yes	49/75 (65)	487/692 (70)	536/767 (70)	273/392 (70)	214/300 (71)
	No	25/75 (33)	191/692 (28)	216/767 (28)	112/392 (29)	79/300 (26)
	Not stated	1/75 (1)	14/692 (2)	15/767 (2)	7/392 (2)	7/300 (2)
What treatment was the patient on?						
Sulfasalazine		2/49 (4)	33/487 (7)	35/536 (7)	22/273 (8)	11/214 (5)
Oral 5-aminosalicylic acid (ASA)		7/49 (14)	96/487 (20)	103/536 (19)	58/273 (21)	38/214 (18)
Topical 5-ASA		0/49 (0)	9/487 (2)	9/536 (2)	6/273 (2)	3/214 (1)
Oral corticosteroids		9/49 (18)	174/487 (36)	183/536 (34)	94/273 (34)	80/214 (37)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Topical corticosteroids		0/49 (0)	5/487 (1)	5/536 (1)	2/273 (1)	3/214 (1)
Mercaptopurine		4/49 (8)	79/487 (16)	83/536 (15)	35/273 (13)	44/214 (21)
Azathioprine		29/49 (59)	174/487 (36)	203/536 (38)	114/273 (42)	60/214 (28)
Methotrexate		7/49 (14)	43/487 (9)	50/536 (9)	24/273 (9)	19/214 (9)
Antibiotics		4/49 (8)	27/487 (6)	31/536 (6)	11/273 (4)	16/214 (7)
Exclusive enteral nutrition	Paediatric only	7/49 (14)		7/49 (14)		
Other dietary therapy	Paediatric only	0/49 (0)		0/49 (0)		
Allopurinol	Paediatric only	1/49 (2)		1/49 (2)		
Dietary therapy	Adult only		3/487 (1)	3/487 (1)	0/273 (0)	3/214 (1)
Anti-TNF agent		20/49 (41)	136/487 (28)	156/536 (29)	70/273 (26)	66/214 (31)
Other (e.g. trial or complementary medicine)		5/49 (10)	29/487 (6)	34/536 (6)	14/273 (5)	15/214 (7)
Was an estimate of compliance recorded?	Yes	5/49 (10)	112/487 (23)	117/536 (22)	60/273 (22)	52/214 (24)
Smoking Status						
What was the patient's smoking status?	Current	1/75 (1)	200/692 (29)	201/767 (26)	101/392 (26)	99/300 (33)
	Not current	11/75 (15)	325/692 (47)	336/767 (44)	192/392 (49)	133/300 (44)
	Not documented	63/75 (84)	167/692 (24)	230/767 (30)	99/392 (25)	68/300 (23)
Other assessment during admission						
Prolonged steroid use						
In the 12 months prior to admission, was the patient taking oral steroids for Crohn's disease (at any time) for more than 3 months?	Yes	8/75 (11)	114/692 (16)	122/767 (16)	58/392 (15)	56/300 (19)
Was an appropriate dose reduction planned?	Yes	5/8 (63)	79/114 (69)	84/122 (69)	40/58 (69)	39/56 (70)
Were bone protection agents used?	Yes	1/8 (13)	36/114 (32)	37/122 (30)	16/58 (28)	20/56 (36)
Was a DEXA scan done within 5 years?	Yes	0/8 (0)	11/114 (10)	11/122 (9)	2/58 (3)	9/56 (16)
What steroid-sparing strategies were tried?						
Thiopurine		8/8 (100)	67/114 (59)	75/122 (61)	30/58 (52)	37/56 (66)
Methotrexate		2/8 (25)	14/114 (12)	16/122 (13)	5/58 (9)	9/56 (16)
Anti-TNF agent		4/8 (50)	39/114 (34)	43/122 (35)	19/58 (33)	20/56 (36)
None		0/8 (0)	22/114 (19)	22/122 (18)	14/58 (24)	8/56 (14)
Other		0/8 (0)	8/114 (7)	8/122 (7)	3/58 (5)	5/56 (9)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Steroid-sparing strategy outcome		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Thiopurine	Ongoing steroid-sparing therapy	6/8 (75)	40/67 (60)	46/75 (61)	19/30 (63)	21/37 (57)
	Stopped - intolerance	1/8 (13)	9/67 (13)	10/75 (13)	4/30 (13)	5/37 (14)
	Stopped - lack of clinical benefit	0/8 (0)	2/67 (3)	2/75 (3)	0/30 (0)	2/37 (5)
	Successful steroid cessation	1/8 (13)	7/67 (10)	8/75 (11)	3/30 (10)	4/37 (11)
	Other	0/8 (0)	9/67 (13)	9/75 (12)	4/30 (13)	5/37 (14)
Methotrexate	Ongoing steroid-sparing therapy	2/2 (100)	10/14 (71)	12/16 (75)	4/5 (80)	6/9 (67)
	Stopped - intolerance	0/2 (0)	2/14 (14)	2/16 (13)	0/5 (0)	2/9 (22)
	Stopped - lack of clinical benefit	0/2 (0)	0/14 (0)	0/16 (0)	0/5 (0)	0/9 (0)
	Successful steroid cessation	0/2 (0)	0/14 (0)	0/16 (0)	0/5 (0)	0/9 (0)
	Other	0/2 (0)	2/14 (14)	2/16 (13)	1/5 (20)	1/9 (11)
Anti-TNF Agent	Ongoing steroid-sparing therapy	3/4 (75)	25/39 (64)	28/43 (65)	12/19 (63)	13/20 (65)
	Stopped - intolerance	1/4 (25)	3/39 (8)	4/43 (9)	2/19 (11)	1/20 (5)
	Stopped - lack of clinical benefit	0/4 (0)	1/39 (3)	1/43 (2)	0/19 (0)	1/20 (5)
	Successful steroid cessation	0/4 (0)	7/39 (18)	7/43 (16)	3/19 (16)	4/20 (20)
	Other	0/4 (0)	3/39 (8)	3/43 (7)	2/19 (11)	1/20 (5)
Other	Ongoing steroid-sparing therapy	0/0	4/8 (50)	4/8 (50)	2/3 (67)	2/5 (40)
	Stopped - intolerance	0/0	1/8 (13)	1/8 (13)	0/3 (0)	1/5 (20)
	Stopped - lack of clinical benefit	0/0	1/8 (13)	1/8 (13)	0/3 (0)	1/5 (20)
	Successful steroid cessation	0/0	0/8 (0)	0/8 (0)	0/3 (0)	0/5 (0)
	Other	0/0	2/8 (25)	2/8 (25)	1/3 (33)	1/5 (20)
Weight assessment and dietetic support during admission						
Was a dietetic assessment recorded?	Yes	46/75 (61)	305/692 (44)	351/767 (46)	153/392 (39)	152/300 (51)
Was a formal nutritional risk assessment documented in the patient record?	Yes	14/75 (19)	291/692 (42)	305/767 (40)	150/392 (38)	141/300 (47)
Nutritional risk assessment by whom?	Nurse	2/14 (14)	104/291 (36)	106/305 (35)	43/150 (29)	61/141 (43)
	Doctor	0/14 (0)	2/291 (1)	2/305 (1)	2/150 (1)	0/141 (0)
	Dietitian	11/14 (79)	154/291 (53)	165/305 (54)	85/150 (57)	69/141 (49)
	Nutrition assistant	0/14 (0)	2/291 (1)	2/305 (1)	0/150 (0)	2/141 (1)
	Unclear	1/14 (7)	29/291 (10)	30/305 (10)	20/150 (13)	9/141 (6)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was the patient's weight recorded within 2 days of admission?	Yes	64/75 (85)	394/692 (57)	458/767 (60)	208/392 (53)	186/300 (62)
Was the patient's height recorded?	Yes. Paediatric only	33/69 (48)		33/69 (48)		
Was the patient's weight recorded within 2 days of discharge?	Yes	33/75 (44)	226/692 (33)	259/767 (34)	111/392 (28)	115/300 (38)
Was BMI recorded?	Yes	28/75 (37)	282/692 (41)	310/767 (40)	143/392 (36)	139/300 (46)
Was it documented that a dietitian saw the patient?	Yes	46/75 (61)	291/692 (42)	337/767 (44)	150/392 (38)	141/300 (47)
	No	26/75 (35)	338/692 (49)	364/767 (47)	197/392 (50)	141/300 (47)
	N/A (well nourished/not needed)	3/75 (4)	63/692 (9)	66/767 (9)	45/392 (11)	18/300 (6)
Was dietary treatment recommended?	Yes	47/75 (63)	303/692 (44)	350/767 (46)	163/392 (42)	140/300 (47)
	No	18/75 (24)	266/692 (38)	284/767 (37)	156/392 (40)	110/300 (37)
	Not recorded	10/75 (13)	123/692 (18)	133/767 (17)	73/392 (19)	50/300 (17)
Investigations						
Results recorded within 24 hours of admission:						
C-reactive protein (CRP)	Yes	62/75 (83)	620/692 (90)	682/767 (89)	362/392 (92)	258/300 (86)
Haemoglobin	Yes	69/75 (92)	674/692 (97)	743/767 (97)	384/392 (98)	290/300 (97)
Albumin	Yes	62/75 (83)	651/692 (94)	713/767 (93)	368/392 (94)	283/300 (94)
Faecal calprotectin	Yes	11/75 (15)	55/692 (8)	66/767 (9)	20/392 (5)	35/300 (12)
Haematocrit	Yes. Paediatric only	63/75 (84)		63/75 (84)		
Erythrocyte sedimentation rate (ESR)	Yes. Paediatric only	27/75 (36)		27/75 (36)		
Was a stool sample sent for stool culture/PCR within 48 hours of admission?	Yes. Excludes 'Not applicable'	33/66 (50)	270/574 (47)	303/640 (47)	152/342 (44)	118/232 (51)
Was stool sample positive?	Yes	2/33 (6)	17/270 (6)	19/303 (6)	9/152 (6)	8/118 (7)
Was stool sample sent for *Clostridium difficile* toxin within 48 hours of admission?	Yes. Excludes 'Not applicable'	25/66 (38)	231/568 (41)	256/634 (40)	128/337 (38)	103/231 (45)
Stool sample positive for *C. difficile* toxin	Yes	0/25 (0)	14/231 (6)	14/256 (5)	5/128 (4)	9/103 (9)
Imaging used during the admission:						
None		17/75 (23)	82/692 (12)	99/767 (13)	45/392 (11)	37/300 (12)
Abdominal X-ray		19/75 (25)	321/692 (46)	340/767 (44)	186/392 (47)	135/300 (45)
Abdominal ultrasound		26/75 (35)	41/692 (6)	67/767 (9)	20/392 (5)	21/300 (7)
Specific small bowel ultrasound		3/75 (4)	4/692 (1)	7/767 (1)	0/392 (0)	4/300 (1)
Abdominal CT scan		10/75 (13)	274/692 (40)	284/767 (37)	180/392 (46)	94/300 (31)
MR enterography		11/75 (15)	66/692 (10)	77/767 (10)	34/392 (9)	32/300 (11)
Other		18/75 (24)	162/692 (23)	180/767 (23)	84/392 (21)	78/300 (26)
Other details: Chest X-ray				106/180		

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Care team and ward		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Which specialty was responsible for the patient's care 24 hours after admission?	Acute or general medicine	2/75 (3)	50/692 (7)	52/767 (7)	46/392 (12)	4/300 (1)
	General surgery	9/75 (12)	77/692 (11)	86/767 (11)	63/392 (16)	14/300 (5)
	Gastroenterology	56/75 (75)	436/692 (63)	492/767 (64)	225/392 (57)	211/300 (70)
	Colorectal surgery	2/75 (3)	116/692 (17)	118/767 (15)	51/392 (13)	65/300 (22)
	Other	6/75 (8)	13/692 (2)	19/767 (2)	7/392 (2)	6/300 (2)
Was a gastroenterology consultant or registrar consulted? (excludes 'Not documented')	Yes	71/74 (96)	614/680 (90)	685/754 (91)	340/383 (89)	274/297 (92)
	No	3/74 (4)	43/680 (6)	46/754 (6)	31/383 (8)	12/297 (4)
	Not required	0/74 (0)	23/680 (3)	23/754 (3)	12/383 (3)	11/297 (4)
Was a colorectal (adult) or paediatric surgical consultant or registrar consulted? (excludes 'Not documented')	Yes	27/73 (37)	341/671 (51)	368/744 (49)	180/375 (48)	161/296 (54)
	No	32/73 (44)	203/671 (30)	235/744 (32)	138/375 (37)	65/296 (22)
	Not required	14/73 (19)	127/671 (19)	141/744 (19)	57/375 (15)	70/296 (24)
An IBD nurse specialist saw the patient during admission	Yes	25/75 (33)	94/692 (14)	119/767 (16)	28/392 (7)	66/300 (22)
Was the patient cared for on a specialist gastroenterology ward?	Yes	17/75 (23)	456/692 (66)	473/767 (62)	207/392 (53)	249/300 (83)
Gastroenterology ward type	Medical	7/17 (41)	160/456 (35)	167/473 (35)	85/207 (41)	75/249 (30)
	Joint medical/surgical	8/17 (47)	243/456 (53)	251/473 (53)	95/207 (46)	148/249 (59)
	Surgical	2/17 (12)	53/456 (12)	55/473 (12)	27/207 (13)	26/249 (10)
Was psychological support provided?	Yes	20/75 (27)	65/692 (9)	85/767 (11)	36/392 (9)	29/300 (10)
	Yes. If patient had a comorbidity of psychological condition			26/104 (25)		
Psychological support provided by:						
Psychologist		10/20 (50)	7/65 (11)	17/85 (20)	2/36 (6)	5/29 (17)
Psychiatrist		5/20 (25)	15/65 (23)	20/85 (24)	9/36 (25)	6/29 (21)
Social worker		11/20 (55)	45/65 (69)	56/85 (66)	27/36 (75)	18/29 (62)
Pastoral		0/20 (0)	4/65 (6)	4/85 (5)	3/36 (8)	1/29 (3)
Other		1/20 (5)	10/65 (15)	11/85 (13)	4/36 (11)	6/29 (21)
Did the patient receive short-term psychotropic medication?	Yes. Excludes 'Not applicable'	4/73 (5)	93/632 (15)	97/705 (14)	49/370 (13)	44/262 (17)
Was patient discussed at a multidisciplinary team meeting?	Yes	12/68 (18)	80/622 (13)	92/690 (13)	24/363 (7)	56/259 (22)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Medical Intervention		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Use of antithrombotic therapy						
Was the patient given prophylaxis for deep vein thrombosis and pulmonary embolism?	Yes	14/75 (19)	540/692 (78)	554/767 (72)	305/392 (78)	235/300 (78)
	No	61/75 (81)	137/692 (20)	198/767 (26)	79/392 (20)	58/300 (19)
	Contraindicated	0/75 (0)	15/692 (2)	15/767 (2)	8/392 (2)	7/300 (2)
Did the patient have a thrombotic episode during this admission?	Yes	0/68 (0)	7/622 (1)	7/690 (1)	5/363 (1)	2/259 (1)
Thrombotic episode - type	Deep vein thrombosis	0/0	2/7 (29)	2/7 (29)	2/5 (40)	0/2 (0)
	Pulmonary embolism	0/0	2/7 (29)	2/7 (29)	1/5 (20)	1/2 (50)
	Other	0/0	3/7 (43)	3/7 (43)	2/5 (40)	1/2 (50)
Steroid and other therapy						
Were corticosteroids initiated during this admission?	Yes. If non-elective patient	24/68 (35)	422/622 (68)	446/690 (65)	255/363 (70)	167/259 (64)
Corticosteroid route of administration:						
Intravenous		19/24 (79)	346/422 (82)	365/446 (82)	213/255 (84)	133/167 (80)
Oral		13/24 (54)	263/422 (62)	276/446 (62)	162/255 (64)	101/167 (60)
Topical		0/24 (0)	5/422 (1)	5/446 (1)	4/255 (2)	1/167 (1)
Other therapies were started during the admission (if non-elective patient)						
None		29/68 (43)	364/622 (59)	393/690 (57)	220/363 (61)	144/259 (56)
5-aminosalicylates		3/68 (4)	45/622 (7)	48/690 (7)	34/363 (9)	11/259 (4)
Thiopurine		10/68 (15)	96/622 (15)	106/690 (15)	59/363 (16)	37/259 (14)
Methotrexate		2/68 (3)	16/622 (3)	18/690 (3)	3/363 (1)	13/259 (5)
Anti-TNF		6/68 (9)	38/622 (6)	44/690 (6)	19/363 (5)	19/259 (7)
Exclusive enteral nutrition	Paediatric only	19/68 (28)		19/68 (28)		
Other		16/68 (24)	102/622 (16)	118/690 (17)	53/363 (15)	49/259 (19)
Other details: antibiotics				85/118		
Surgical Intervention						
Did the patient have surgery on this admission?	Yes	12/75 (16)	156/692 (23)	168/767 (22)	77/392 (20)	79/300 (26)
Was there a delay of more than 48 hours between decision to operate and surgery for non-elective patients?	Yes. Excludes 'Unclear'	0/5 (0)	7/72 (10)	7/77 (9)	1/41 (2)	6/31 (19)

Crohn's disease			Age (years)			Partial IBD Service (18 years and over)	
			Under 18	18 and over	All	No	Yes
			n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Reason for surgery delay		Ulcerative colitis improvement	0/0	0/7 (0)	0/7 (0)	0/1 (0)	0/6 (0)
		Cancelled - resource reasons	0/0	2/7 (29)	2/7 (29)	0/1 (0)	2/6 (33)
		Cancelled - clinical reasons	0/0	1/7 (14)	1/7 (14)	0/1 (0)	1/6 (17)
		Patient declined	0/0	2/7 (29)	2/7 (29)	1/1 (100)	1/6 (17)
		Unclear	0/0	1/7 (14)	1/7 (14)	0/1 (0)	1/6 (17)
		Other	0/0	1/7 (14)	1/7 (14)	0/1 (0)	1/6 (17)
Was the ASA status recorded on an anaesthetic chart?		Yes	9/12 (75)	127/156 (81)	136/168 (81)	63/77 (82)	64/79 (81)
What was the ASA status value?							
	1	Excludes 'Not applicable'	1/9 (11)	16/126 (13)	17/135 (13)	10/62 (16)	6/64 (9)
	2	Excludes 'Not applicable'	6/9 (67)	82/126 (65)	88/135 (65)	37/62 (60)	45/64 (70)
	3	Excludes 'Not applicable'	2/9 (22)	25/126 (20)	27/135 (20)	14/62 (23)	11/64 (17)
	4	Excludes 'Not applicable'	0/9 (0)	3/126 (2)	3/135 (2)	1/62 (2)	2/64 (3)
What were the indications for this surgery?							
Obstruction			2/12 (17)	42/156 (27)	44/168 (26)	16/77 (21)	26/79 (33)
Perforation			0/12 (0)	22/156 (14)	22/168 (13)	11/77 (14)	11/79 (14)
Abscess			6/12 (50)	36/156 (23)	42/168 (25)	19/77 (25)	17/79 (22)
Ileostomy formation			1/12 (8)	12/156 (8)	13/168 (8)	5/77 (6)	7/79 (9)
Stoma closure			2/12 (17)	7/156 (4)	9/168 (5)	5/77 (6)	2/79 (3)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Medical therapy fail		2/12 (17)	35/156 (22)	37/168 (22)	16/77 (21)	19/79 (24)
Bleeding		1/12 (8)	6/156 (4)	7/168 (4)	3/77 (4)	3/79 (4)
Completion proctectomy		0/12 (0)	4/156 (3)	4/168 (2)	1/77 (1)	3/79 (4)
Dysplasia		0/12 (0)	0/156 (0)	0/168 (0)	0/77 (0)	0/79 (0)
Cancer		0/12 (0)	1/156 (1)	1/168 (1)	1/77 (1)	0/79 (0)
Fistula	Paediatric only	0/12 (0)		0/12 (0)		
Other		2/12 (17)	50/156 (32)	52/168 (31)	29/77 (38)	21/79 (27)
Type of intervention:						
Ileocolonic resection		1/12 (8)	69/156 (44)	70/168 (42)	33/77 (43)	36/79 (46)
Ileal/jejunal resection		1/12 (8)	11/156 (7)	12/168 (7)	2/77 (3)	9/79 (11)
Strictureplasty		0/12 (0)	4/156 (3)	4/168 (2)	1/77 (1)	3/79 (4)
Segmental/extended colectomy		0/12 (0)	10/156 (6)	10/168 (6)	5/77 (6)	5/79 (6)
Subtotal colectomy		1/12 (8)	18/156 (12)	19/168 (11)	6/77 (8)	12/79 (15)
Proctocolectomy		0/12 (0)	3/156 (2)	3/168 (2)	1/77 (1)	2/79 (3)
Intra-abdominal fistula resection		0/12 (0)	7/156 (4)	7/168 (4)	5/77 (6)	2/79 (3)
Completion proctectomy		0/12 (0)	4/156 (3)	4/168 (2)	2/77 (3)	2/79 (3)
Abscess drainage		6/12 (50)	17/156 (11)	23/168 (14)	6/77 (8)	11/79 (14)
Formation of ileostomy or colostomy		1/12 (8)	25/156 (16)	26/168 (15)	13/77 (17)	12/79 (15)
Revision of stoma		0/12 (0)	1/156 (1)	1/168 (1)	1/77 (1)	0/79 (0)
Closure of stoma		2/12 (17)	7/156 (4)	9/168 (5)	5/77 (6)	2/79 (3)
Perineal procedure		1/12 (8)	7/156 (4)	8/168 (5)	3/77 (4)	4/79 (5)
Division of adhesions		0/12 (0)	24/156 (15)	24/168 (14)	9/77 (12)	15/79 (19)
Seton insertion	Paediatric only	3/12 (25)		3/12 (25)		
Other		3/12 (25)	38/156 (24)	41/168 (24)	22/77 (29)	16/79 (20)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was the surgery done laparoscopically or laparoscopically assisted?	Yes	3/12 (25)	77/156 (49)	80/168 (48)	35/77 (45)	42/79 (53)
	No	9/12 (75)	78/156 (50)	87/168 (52)	41/77 (53)	37/79 (47)
	Unclear	0/12 (0)	1/156 (1)	1/168 (1)	1/77 (1)	0/79 (0)
Was the patient seen by a stoma nurse during this admission?*	Yes	3/5 (60)	53/116 (46)	56/121 (46)	25/55 (45)	28/61 (46)
	No	2/5 (40)	57/116 (49)	59/121 (49)	26/55 (47)	31/61 (51)
	Unclear	0/5 (0)	6/116 (5)	6/121 (5)	4/55 (7)	2/61 (3)
Was the patient seen by a stoma nurse before surgery?*	Yes	3/5 (60)	32/116 (28)	35/121 (29)	15/55 (27)	17/61 (28)
	No	1/5 (20)	57/116 (49)	58/121 (48)	25/55 (45)	32/61 (52)
	Unclear	1/5 (20)	27/116 (23)	28/121 (23)	15/55 (27)	12/61 (20)
*Excludes strictureplasty, abscess drainage, perineal procedure, adhesion division, seton insertion, other						
Surgical complications						
Did the patient develop postoperative complications? (Only includes patients who had surgery):	Yes	3/12 (25)	50/156 (32)	53/168 (32)	25/77 (32)	25/79 (32)
Wound Infection		1/12 (8)	12/156 (8)	13/168 (8)	4/77 (5)	8/79 (10)
Rectal stump complications		0/12 (0)	0/156 (0)	0/168 (0)	0/77 (0)	0/79 (0)
Intra-abdominal bleeding		0/12 (0)	1/156 (1)	1/168 (1)	0/77 (0)	1/79 (1)
Intra-abdominal abscess		0/12 (0)	4/156 (3)	4/168 (2)	1/77 (1)	3/79 (4)
Anastomotic leakage		0/12 (0)	8/156 (5)	8/168 (5)	3/77 (4)	5/79 (6)
Stoma complications		0/12 (0)	3/156 (2)	3/168 (2)	1/77 (1)	2/79 (3)
Deep vein thrombosis (DVT)		0/12 (0)	0/156 (0)	0/168 (0)	0/77 (0)	0/79 (0)
Pulmonary embolism (PE)		0/12 (0)	0/156 (0)	0/168 (0)	0/77 (0)	0/79 (0)
Small bowel obstruction		0/12 (0)	1/156 (1)	1/168 (1)	1/77 (1)	0/79 (0)
Ileus		1/12 (8)	17/156 (11)	18/168 (11)	7/77 (9)	10/79 (13)
Total parenteral nutrition (TPN)		2/12 (17)	9/156 (6)	11/168 (7)	4/77 (5)	5/79 (6)
Cardiac		0/12 (0)	3/156 (2)	3/168 (2)	1/77 (1)	2/79 (3)
Respiratory		0/12 (0)	6/156 (4)	6/168 (4)	3/77 (4)	3/79 (4)
Clostridium difficile-associated diarrhoea		1/12 (8)	0/156 (0)	1/168 (1)	0/77 (0)	0/79 (0)
Malnutrition		0/12 (0)	4/156 (3)	4/168 (2)	1/77 (1)	3/79 (4)
Reoperation (for any reason)		1/12 (8)	7/156 (4)	8/168 (5)	2/77 (3)	5/79 (6)
Other		1/12 (8)	21/156 (13)	22/168 (13)	10/77 (13)	11/79 (14)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was the patient prescribed new extra drugs on discharge? (Only includes patients who had surgery):		6/12 (50)	53/156 (34)	59/168 (35)	18/77 (23)	35/79 (44)
Newly prescribed azathioprine		1/12 (8)	11/156 (7)	12/168 (7)	4/77 (5)	7/79 (9)
Newly prescribed mercaptopurine		0/12 (0)	4/156 (3)	4/168 (2)	1/77 (1)	3/79 (4)
Newly prescribed metronidazole		1/12 (8)	20/156 (13)	21/168 (13)	6/77 (8)	14/79 (18)
Newly prescribed 5-ASA		1/12 (8)	1/156 (1)	2/168 (1)	0/77 (0)	1/79 (1)
Newly prescribed methotrexate		0/12 (0)	3/156 (2)	3/168 (2)	0/77 (0)	3/79 (4)
Newly prescribed infliximab		2/12 (17)	3/156 (2)	5/168 (3)	1/77 (1)	2/79 (3)
Newly prescribed adalimumab		0/12 (0)	3/156 (2)	3/168 (2)	1/77 (1)	2/79 (3)
Newly prescribed other		3/12 (25)	16/156 (10)	19/168 (11)	7/77 (9)	9/79 (11)
Anaemia						
Was the patient anaemic on admission?	Yes	36/75 (48)	211/692 (30)	247/767 (32)	124/392 (32)	87/300 (29)
	No	33/75 (44)	462/692 (67)	495/767 (65)	257/392 (66)	205/300 (68)
	Not recorded	6/75 (8)	19/692 (3)	25/767 (3)	11/392 (3)	8/300 (3)
Was the anaemia noted or commented on by the treating team?	Yes	26/36 (72)	121/211 (57)	147/247 (60)	69/124 (56)	52/87 (60)
	No	5/36 (14)	63/211 (30)	68/247 (28)	36/124 (29)	27/87 (31)
	Not recorded	5/36 (14)	27/211 (13)	32/247 (13)	19/124 (15)	8/87 (9)
Was anaemia at presentation due to iron deficiency?	Yes	19/36 (53)	79/211 (37)	98/247 (40)	45/124 (36)	34/87 (39)
	No	4/36 (11)	34/211 (16)	38/247 (15)	21/124 (17)	13/87 (15)
	Other cause/ uncertain	2/36 (6)	34/211 (16)	36/247 (15)	16/124 (13)	18/87 (21)
	Not recorded	11/36 (31)	64/211 (30)	75/247 (30)	42/124 (34)	22/87 (25)
What treatment was administered for anaemia?						
Oral iron		4/19 (21)	5/79 (6)	9/98 (9)	5/45 (11)	0/34 (0)
Intravenous iron		13/19 (68)	51/79 (65)	64/98 (65)	28/45 (62)	23/34 (68)
Blood transfusion		1/19 (5)	15/79 (19)	16/98 (16)	10/45 (22)	5/34 (15)
Nutritional advice		1/19 (5)	2/79 (3)	3/98 (3)	0/45 (0)	2/34 (6)
Not recorded		1/19 (5)	17/79 (22)	18/98 (18)	8/45 (18)	9/34 (26)

Crohn's disease		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Discharge arrangements		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was the patient taking oral steroids on discharge?	Yes	25/72 (35)	430/674 (64)	455/746 (61)	252/379 (66)	178/295 (60)
	No	46/72 (64)	238/674 (35)	284/746 (38)	127/379 (34)	111/295 (38)
	Not applicable	1/72 (1)	6/674 (1)	7/746 (1)	0/379 (0)	6/295 (2)
For those on steroids was a steroid reduction program stated on discharge?	Yes	21/25 (84)	366/430 (85)	387/455 (85)	205/252 (81)	161/178 (90)
	No	4/25 (16)	55/430 (13)	59/455 (13)	41/252 (16)	14/178 (8)
	Not applicable	0/25 (0)	9/430 (2)	9/455 (2)	6/252 (2)	3/178 (2)
For those on steroids were bone protection agents prescribed?	Yes	5/25 (20)	114/430 (27)	119/455 (26)	55/252 (22)	59/178 (33)
	No	20/25 (80)	307/430 (71)	327/455 (72)	190/252 (75)	117/178 (66)
	Not applicable	0/25 (0)	9/430 (2)	9/455 (2)	7/252 (3)	2/178 (1)
Was ongoing nutritional supplementation recommended on discharge?	Yes	38/72 (53)	152/674 (23)	190/746 (25)	71/379 (19)	81/295 (27)
	No	30/72 (42)	470/674 (70)	500/746 (67)	288/379 (76)	182/295 (62)
	Not applicable	4/72 (6)	52/674 (8)	56/746 (8)	20/379 (5)	32/295 (11)
Were arrangements made for follow up by a dietitian?	Yes	33/72 (46)	106/674 (16)	139/746 (19)	39/379 (10)	67/295 (23)
	No	36/72 (50)	505/674 (75)	541/746 (73)	320/379 (84)	185/295 (63)
	Not applicable	3/72 (4)	63/674 (9)	66/746 (9)	20/379 (5)	43/295 (15)
	Yes. If they had ongoing nutritional supplementation recommended	29/38 (76)	78/152 (51)	107/190 (56)	27/71 (38)	51/81 (63)
Was the patient on immunosuppressive drugs on discharge?	Yes	48/72 (67)	382/674 (57)	430/746 (58)	216/379 (57)	166/295 (56)
	No	21/72 (29)	286/674 (42)	307/746 (41)	162/379 (43)	124/295 (42)
	Not applicable	3/72 (4)	6/674 (1)	9/746 (1)	1/379 (<1)	5/295 (2)
Was a plan for safety monitoring of immunosupressive drugs implemented?	Yes	34/48 (71)	254/382 (66)	288/430 (67)	117/216 (54)	137/166 (83)
Was there a plan for maintenance anti-TNF on discharge?	Yes	29/72 (40)	165/674 (24)	194/746 (26)	88/379 (23)	77/295 (26)
	No	32/72 (44)	416/674 (62)	448/746 (60)	222/379 (59)	194/295 (66)
	Not applicable	11/72 (15)	93/674 (14)	104/746 (14)	69/379 (18)	24/295 (8)
Was a plan for safety monitoring of anti-TNF implemented?	Yes	17/29 (59)	118/165 (72)	135/194 (70)	47/88 (53)	71/77 (92)

Crohn's disease	Age (years)			Partial IBD Service (18 years and over)	
	Under 18	18 and over	All	No	Yes
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Patients discharged on oral steroids, immunosuppressive drugs or anti-TNF agents (derived)			616/767 (80)		
Were psychological or behavioural factors identified to contribute to poor disease management? Yes	12/72 (17)	51/674 (8)	63/746 (8)	29/379 (8)	22/295 (7)
No	51/72 (71)	513/674 (76)	564/746 (76)	281/379 (74)	232/295 (79)
Unclear	9/72 (13)	110/674 (16)	119/746 (16)	69/379 (18)	41/295 (14)
Was an outpatient psychological plan put in place. Yes	8/12 (67)	27/51 (53)	35/63 (56)	13/29 (45)	14/22 (64)
Was a plan for follow-up documented in the discharge summary? Yes	67/72 (93)	639/674 (95)	706/746 (95)	356/379 (94)	283/295 (96)
Was discharge summary sent/faxed/emailed to the patient's general practitioner? Yes	62/72 (86)	556/674 (82)	618/746 (83)	302/379 (80)	254/295 (86)
No	4/72 (6)	31/674 (5)	35/746 (5)	23/379 (6)	8/295 (3)
Unclear	6/72 (8)	87/674 (13)	93/746 (12)	54/379 (14)	33/295 (11)
Outpatient care before admission					
Patient had previous outpatient visits or private practice consultation for IBD. Yes	51/75 (68)	498/692 (72)	549/767 (72)	275/392 (70)	223/300 (74)
No	21/75 (28)	143/692 (21)	164/767 (21)	84/392 (21)	59/300 (20)
unknown	3/75 (4)	51/692 (7)	54/767 (7)	33/392 (8)	18/300 (6)

Crohn's disease	Age (years)			Partial IBD Service (18 years and over)	
	Under 18	18 and over	All	No	Yes
	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
Number of times patient seen in 12 months before start date of this admission	N=34 3 (2, 6)	N=258 3 (2, 5)	N=292 3 (2, 5)	N=101 3 (2, 5)	N=157 3 (2, 4)
	n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was disease active at last outpatient department appointment or private practice review? Yes	22/51 (43)	225/498 (45)	247/549 (45)	98/275 (36)	127/223 (57)

Note: Percentages may not sum exactly to 100%, where relevant, due to rounding.

Ulcerative colitis data tables

Ulcerative colitis	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
Number of sites		N=21	N=45	N=50		
Cases per site		1 (1, 3)	14 (7, 20)	12 (7, 20)		
Demographics		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Age on admission (years)	0-8	12/69 (17)		12/673 (2)		
	9 -17	57/69 (83)		57/673 (8)		
	18-29		209/604 (35)	209/673 (31)	118/328 (36)	91/276 (33)
	30-39		148/604 (25)	148/673 (22)	79/328 (24)	69/276 (25)
	40-49		83/604 (14)	83/673 (12)	48/328 (15)	35/276 (13)
	50-59		67/604 (11)	67/673 (10)	29/328 (9)	38/276 (14)
	60-69		44/604 (7)	44/673 (7)	22/328 (7)	22/276 (8)
	70+		53/604 (9)	53/673 (9)	32/328 (10)	21/276 (8)
Gender	Female	32/69 (46)	289/604 (48)	321/673 (48)	154/328 (47)	135/276 (49)
	Male	37/69 (54)	313/604 (52)	350/673 (52)	174/328 (53)	139/276 (50)
	Other	0/69 (0)	2/604 (<1)	2/673 (<1)	0/328 (0)	2/276 (1)
Admission / discharge						
What was the primary reason for admission?	New diagnosis	14/69 (20)	85/604 (14)	99/673 (15)	48/328 (15)	37/276 (13)
	Emergency admission	36/69 (52)	365/604 (60)	401/673 (60)	210/328 (64)	155/276 (56)
	Planned admission (known case)	8/69 (12)	52/604 (9)	60/673 (9)	24/328 (7)	28/276 (10)
	Elective admission for surgery	8/69 (12)	51/604 (8)	59/673 (9)	26/328 (8)	25/276 (9)
	Transfer from another site	2/69 (3)	29/604 (5)	31/673 (5)	10/328 (3)	19/276 (7)
	Other	1/69 (1)	22/604 (4)	23/673 (3)	10/328 (3)	12/276 (4)
Source of admission						
Emergency department		39/69 (57)	395/604 (65)	434/673 (64)	237/328 (72)	158/276 (57)
Referred by GP		2/69 (3)	34/604 (6)	36/673 (5)	25/328 (8)	9/276 (3)
Advised to attend by IBD nurse helpline		0/69 (0)	17/604 (3)	17/673 (3)	2/328 (1)	15/276 (5)
Referred in from hospital outpatient department		14/69 (20)	52/604 (9)	66/673 (10)	29/328 (9)	23/276 (8)
Refereed in from gastroenterologist rooms		5/69 (7)	65/604 (11)	70/673 (10)	35/328 (11)	30/276 (11)
Referred in from surgical specialist rooms		4/69 (6)	30/604 (5)	34/673 (5)	15/328 (5)	15/276 (5)
Transfer from another site		8/69 (12)	40/604 (7)	48/673 (7)	15/328 (5)	25/276 (9)
Other		1/69 (1)	25/604 (4)	26/673 (4)	8/328 (2)	17/276 (6)

Ulcerative colitis		Age (years) Under 18	18 and over	All	Partial IBD Service (18 years and over) No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Demographics						
Overnight admissions with ulcerative colitis in the two years prior to this admission at this hospital		35/69 (51)	213/604 (35)	248/673 (37)	121/328 (37)	92/276 (33)
		Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	median (Q1, Q3)
		N=35	N=213	N=248	N=121	N=92
Previous admissions: how many times in the 2 years before this admission?		2 (1, 3)	1 (1, 2)	1 (1, 2)	1 (1, 2)	1 (1, 2)
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Has there been an ulcerative colitis -related admission within the last 30 days? Yes		8/35 (23)	59/213 (28)	67/248 (27)	31/121 (26)	28/92 (30)
Where was the patient discharged to?	Home	67/69 (97)	567/604 (94)	634/673 (94)	304/328 (93)	263/276 (95)
	Own risk	0/69 (0)	6/604 (1)	6/673 (1)	2/328 (1)	4/276 (1)
	Nursing home/rehab	0/69 (0)	12/604 (2)	12/673 (2)	5/328 (2)	7/276 (3)
	Transfer - surgery	1/69 (1)	5/604 (1)	6/673 (1)	3/328 (1)	2/276 (1)
	Transfer - medical management	1/69 (1)	14/604 (2)	15/673 (2)	14/328 (4)	0/276 (0)
	Deceased	0/69 (0)	0/604 (0)	0/673 (0)	0/328 (0)	0/276 (0)
		Mean	Mean	Mean	Mean	Mean
Length of stay (excludes three cases where admission date=discharge date)		10.2	8.1	8.3	8.2	7.9
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
1-2 days		12 (17)	63 (10)	75 (11)	38 (12)	25 (9)
3-6 days		36 (52)	289 (48)	325 (49)	159 (49)	130 (47)
7-13 days		16 (23)	171 (28)	187 (28)	90 (28)	81 (30)
14-27 days		2 (3)	62 (10)	64 (10)	31 (9)	31 (11)
28+ days		3 (4)	16 (3)	19 (3)	9 (3)	7 (3)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Initial assessment during the first full day following admission						
Was duration of disease stated in admission notes?	Yes. Excludes new diagnoses	38/55 (69)	386/517 (75)	424/572 (74)	210/279 (75)	176/238 (74)
Duration of disease (years), excludes new diagnoses	< 1	14/38 (37)	52/386 (13)	66/424 (16)	27/210 (13)	25/176 (14)
	1-< 2	7/38 (18)	54/386 (14)	61/424 (14)	35/210 (17)	19/176 (11)
	2-< 5	10/38 (26)	99/386 (26)	109/424 (26)	54/210 (26)	45/176 (26)
	5-< 10	7/38 (18)	79/386 (20)	86/424 (20)	42/210 (20)	37/176 (21)
	10+	0/38 (0)	102/386 (26)	102/424 (24)	52/210 (25)	50/176 (28)
		maximum = 7	maximum = 44	maximum = 44	maximum = 44	maximum = 42
Was the extent of the disease recorded in admission notes?	Yes. Excludes new diagnoses	23/55 (42)	273/517 (53)	296/572 (52)	140/279 (50)	133/238 (56)
What was the extent of disease recorded?		1/23 (4)	52/273 (19)	53/296 (18)	27/140 (19)	25/133 (19)
Proctis		5/23 (22)	102/273 (37)	107/296 (36)	47/140 (34)	55/133 (41)
Left-sided		0/23 (0)		0/23 (0)		
Caecal patch (paediatric only)		15/23 (65)	101/273 (37)	116/296 (39)	56/140 (40)	45/133 (34)
Extensive		2/23 (9)	4/273 (1)	6/296 (2)	3/140 (2)	1/133 (1)
IBD-unclassified		0/23 (0)	14/273 (5)	14/296 (5)	7/140 (5)	7/133 (5)
Unknown						
Severity of disease activity recorded in the first 24 hours (Paediatric: e.g. PUCAI)?	Yes	15/69 (22)	421/601 (70)	436/670 (65)	214/326 (66)	207/275 (75)
Was the number of loose stools passed in the first full day after admission recorded?	Yes. Excludes 'Not applicable' and 'Stoma'	45/60 (75)	441/546 (81)	486/606 (80)	246/297 (83)	195/249 (78)
Was the number of bloody stools passed in the first full day after admission recorded?	Yes. Excludes 'Not applicable'	38/59 (64)	387/553 (70)	425/612 (69)	219/303 (72)	168/250 (67)
Did the notes record current presence of fevers?	Yes	11/69 (16)	158/601 (26)	169/670 (25)	85/326 (26)	73/275 (27)
Was the presence of nocturnal stools documented in the clinical record?	Yes	28/69 (41)	212/601 (35)	240/670 (36)	103/326 (32)	109/275 (40)
Was the presence of urgency or incontinence documented in the clinical record?	Yes	17/69 (25)	127/601 (21)	144/670 (21)	56/326 (17)	71/275 (26)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Did the notes record current presence of:						
Mouth ulcers?	Yes	5/69 (7)	16/601 (3)	21/670 (3)	8/326 (2)	8/275 (3)
Arthralgia	Yes	2/69 (3)	47/601 (8)	49/670 (7)	28/326 (9)	19/275 (7)
Arthritis	Yes	1/69 (1)	22/601 (4)	23/670 (3)	15/326 (5)	7/275 (3)
Ankylosing spondylitis	Yes	0/69 (0)	5/601 (1)	5/670 (1)	4/326 (1)	1/275 (<1)
Erythema nodosum	Yes	0/69 (0)	3/601 (<1)	3/670 (<1)	2/326 (1)	1/275 (<1)
Pyoderma gangrenosum	Yes	0/69 (0)	3/601 (<1)	3/670 (<1)	1/326 (<1)	2/275 (1)
Iritis	Yes	1/69 (1)	3/601 (<1)	4/670 (1)	3/326 (1)	0/275 (0)
Anal fissure	Yes	1/69 (1)	11/601 (2)	12/670 (2)	5/326 (2)	6/275 (2)
Fistula	Yes	0/69 (0)	10/601 (2)	10/670 (1)	6/326 (2)	4/275 (1)
Abscess	Yes	0/69 (0)	12/601 (2)	12/670 (2)	8/326 (2)	4/275 (1)
Malnutrition	Yes	17/69 (25)	88/601 (15)	105/670 (16)	39/326 (12)	49/275 (18)
Comorbidity						
Were any significant comorbid diseases documented?	Yes	19/69 (28)	288/601 (48)	307/670 (46)	166/326 (51)	122/275 (44)
	Statement that there were no relevant comorbidities	26/69 (38)	135/601 (22)	161/670 (24)	55/326 (17)	80/275 (29)
	None recorded	24/69 (35)	178/601 (30)	202/670 (30)	105/326 (32)	73/275 (27)
Which comorbidities were recorded?						
Cardiovascular		2/19 (11)	68/288 (24)	70/307 (23)	37/166 (22)	31/122 (25)
Respiratory		2/19 (11)	42/288 (15)	44/307 (14)	23/166 (14)	19/122 (16)
Renal		1/19 (5)	7/288 (2)	8/307 (3)	5/166 (3)	2/122 (2)
Diabetes		0/19 (0)	29/288 (10)	29/307 (9)	16/166 (10)	13/122 (11)
Liver disease		2/19 (11)	17/288 (6)	19/307 (6)	12/166 (7)	5/122 (4)
Active cancer		0/19 (0)	6/288 (2)	6/307 (2)	4/166 (2)	2/122 (2)
Iron deficiency anaemia	Paediatric only	1/19 (5)		1/19 (5)		
Psychological condition		2/19 (11)	75/288 (26)	77/307 (25)	43/166 (26)	32/122 (26)
Other		13/19 (68)	173/288 (60)	186/307 (61)	98/166 (59)	75/122 (61)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Medication on admission						
Was the patient recorded as being on treatment for ulcerative colitis on admission?	Yes	43/69 (62)	433/601 (72)	476/670 (71)	242/326 (74)	191/275 (69)
	No	24/69 (35)	158/601 (26)	182/670 (27)	81/326 (25)	77/275 (28)
	Not stated	2/69 (3)	10/601 (2)	12/670 (2)	3/326 (1)	7/275 (3)
What treatment was the patient on?						
Sulfasalazine		6/43 (14)	64/433 (15)	70/476 (15)	45/242 (19)	19/191 (10)
Oral 5- aminosalicylic acid (ASA)		20/43 (47)	274/433 (63)	294/476 (62)	156/242 (64)	118/191 (62)
Topical 5-ASA		2/43 (5)	85/433 (20)	87/476 (18)	55/242 (23)	30/191 (16)
Oral corticosteroids		22/43 (51)	210/433 (48)	232/476 (49)	123/242 (51)	87/191 (46)
Topical corticosteroids		3/43 (7)	30/433 (7)	33/476 (7)	16/242 (7)	14/191 (7)
Mercaptopurine		3/43 (7)	50/433 (12)	53/476 (11)	25/242 (10)	25/191 (13)
Azathioprine		20/43 (47)	102/433 (24)	122/476 (26)	58/242 (24)	44/191 (23)
Methotrexate		1/43 (2)	11/433 (3)	12/476 (3)	5/242 (2)	6/191 (3)
Antibiotics		2/43 (5)	7/433 (2)	9/476 (2)	3/242 (1)	4/191 (2)
Dietary therapy		1/43 (2)	6/433 (1)	7/476 (1)	3/242 (1)	3/191 (2)
Anti-TNF agent		5/43 (12)	21/433 (5)	26/476 (5)	10/242 (4)	11/191 (6)
Other (e.g. trial or complementary medicine)		12/43 (28)	37/433 (9)	49/476 (10)	16/242 (7)	21/191 (11)
Other details: Tacrolimus				Sep-49		
Was an estimate of compliance recorded?	Yes	6/43 (14)	95/433 (22)	101/476 (21)	64/242 (26)	31/191 (16)
Smoking status						
What was the patient's smoking status?	Current	1/69 (1)	49/601 (8)	50/670 (7)	28/326 (9)	21/275 (8)
	Not current	16/69 (23)	358/601 (60)	374/670 (56)	195/326 (60)	163/275 (59)
	Not documented	52/69 (75)	194/601 (32)	246/670 (37)	103/326 (32)	91/275 (33)
Other assessment during admission						
Prolonged steroid use						
In the 12 months prior to admission, was the patient taking oral steroids for ulcerative colitis (at any time) for more than 3 months	Yes	14/69 (20)	99/601 (16)	113/670 (17)	46/326 (14)	53/275 (19)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was an appropriate dose reduction planned?	Yes	13/14 (93)	64/99 (65)	77/113 (68)	26/46 (57)	38/53 (72)
Were bone protection agents used?	Yes	3/14 (21)	27/99 (27)	30/113 (27)	11/46 (24)	16/53 (30)
Was a DEXA scan done within 5 years?	Yes	1/14 (7)	9/99 (9)	10/113 (9)	3/46 (7)	6/53 (11)
What steroid sparing strategies were tried?						
Thiopurine		12/14 (86)	48/99 (48)	60/113 (53)	18/46 (39)	30/53 (57)
Methotrexate		0/14 (0)	8/99 (8)	8/113 (7)	3/46 (7)	5/53 (9)
Anti-TNF agent		3/14 (21)	14/99 (14)	17/113 (15)	9/46 (20)	5/53 (9)
None		2/14 (14)	32/99 (32)	34/113 (30)	18/46 (39)	14/53 (26)
Other		1/14 (7)	10/99 (10)	11/113 (10)	2/46 (4)	8/53 (15)
Steroid sparing strategy outcome						
Thiopurine	Ongoing steroid-sparing therapy	9/12 (75)	27/48 (56)	36/60 (60)	12/18 (67)	15/30 (50)
	Stopped - intolerance	0/12 (0)	9/48 (19)	9/60 (15)	1/18 (6)	8/30 (27)
	Stopped - lack of clinical benefit	1/12 (8)	3/48 (6)	4/60 (7)	3/18 (17)	0/30 (0)
	Successful steroid cessation	2/12 (17)	3/48 (6)	5/60 (8)	0/18 (0)	3/30 (10)
	Other	0/12 (0)	6/48 (13)	6/60 (10)	2/18 (11)	4/30 (13)
Methotrexate	Ongoing steroid-sparing therapy	0/0	4/8 (50)	4/8 (50)	1/3 (33)	3/5 (60)
	Stopped - intolerance	0/0	1/8 (13)	1/8 (13)	0/3 (0)	1/5 (20)
	Stopped, - lack of clinical benefit	0/0	2/8 (25)	2/8 (25)	1/3 (33)	1/5 (20)
	Successful steroid cessation	0/0	0/8 (0)	0/8 (0)	0/3 (0)	0/5 (0)
	Other	0/0	1/8 (13)	1/8 (13)	1/3 (33)	0/5 (0)
Anti-TNF Agent	Ongoing steroid-sparing therapy	2/3 (67)	5/14 (36)	7/17 (41)	4/9 (44)	1/5 (20)
	Stopped - intolerance	0/3 (0)	2/14 (14)	2/17 (12)	1/9 (11)	1/5 (20)
	Stopped - lack of clinical benefit	0/3 (0)	4/14 (29)	4/17 (24)	3/9 (33)	1/5 (20)
	Successful steroid cessation	1/3 (33)	0/14 (0)	1/17 (6)	0/9 (0)	0/5 (0)
	Other	0/3 (0)	3/14 (21)	3/17 (18)	1/9 (11)	2/5 (40)
Other	Ongoing steroid-sparing therapy	1/1 (100)	6/10 (60)	7/11 (64)	1/2 (50)	5/8 (63)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
	Stopped - intolerance	0/1 (0)	1/10 (10)	1/11 (9)	0/2 (0)	1/8 (13)
	Stopped - lack of clinical benefit	0/1 (0)	2/10 (20)	2/11 (18)	1/2 (50)	1/8 (13)
	Successful steroid cessation	0/1 (0)	1/10 (10)	1/11 (9)	0/2 (0)	1/8 (13)
	Other	0/1 (0)	0/10 (0)	0/11 (0)	0/2 (0)	0/8 (0)
Weight assessment and dietetic support during admission						
Was a dietetic assessment recorded?	Yes	23/69 (33)	286/601 (48)	309/670 (46)	135/326 (41)	151/275 (55)
Was a formal nutritional risk assessment documented in the patient record?	Yes	9/69 (13)	245/601 (41)	254/670 (38)	110/326 (34)	135/275 (49)
Nutritional risk assessment by whom?	Nurse	0/9 (0)	80/245 (33)	80/254 (31)	41/110 (37)	39/135 (29)
	Doctor	1/9 (11)	1/245 (<1)	2/254 (1)	1/110 (1)	0/135 (0)
	Dietitian	7/9 (78)	127/245 (52)	134/254 (53)	56/110 (51)	71/135 (53)
	Nutrition assistant	0/9 (0)	9/245 (4)	9/254 (4)	0/110 (0)	9/135 (7)
	Unclear	1/9 (11)	28/245 (11)	29/254 (11)	12/110 (11)	16/135 (12)
Was the patient's weight recorded within 2 days of admission?	Yes	55/69 (80)	366/601 (61)	421/670 (63)	194/326 (60)	172/275 (63)
Was the patient's height recorded?	Yes. Paediatric only	28/66 (42)		28/66 (42)		
Was the patient's weight recorded within 2 days of discharge?	Yes	24/69 (35)	215/601 (36)	239/670 (36)	115/326 (35)	100/275 (36)
Was BMI recorded?	Yes	20/69 (29)	279/601 (46)	299/670 (45)	129/326 (40)	150/275 (55)
Was it documented that a dietitian saw the patient?	Yes	20/69 (29)	262/601 (44)	282/670 (42)	130/326 (40)	132/275 (48)
	No	45/69 (65)	253/601 (42)	298/670 (44)	152/326 (47)	101/275 (37)
	N/A (well-nourished/not needed)	4/69 (6)	86/601 (14)	90/670 (13)	44/326 (13)	42/275 (15)
Was dietary treatment recommended?	Yes	22/69 (32)	269/601 (45)	291/670 (43)	137/326 (42)	132/275 (48)
	No	29/69 (42)	217/601 (36)	246/670 (37)	114/326 (35)	103/275 (37)
	Not recorded	18/69 (26)	115/601 (19)	133/670 (20)	75/326 (23)	40/275 (15)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Investigations						
Results recorded within 24 hours of admission:						
C-reactive protein (CRP)	Yes	60/69 (87)	552/604 (91)	612/673 (91)	301/328 (92)	251/276 (91)
Haematocrit	Yes. Paediatric only	63/69 (91)		63/69 (91)		
Haemoglobin	Yes	67/69 (97)	590/604 (98)	657/673 (98)	323/328 (98)	267/276 (97)
Albumin	Yes	61/69 (88)	566/604 (94)	627/673 (93)	304/328 (93)	262/276 (95)
Faecal calprotectin	Yes	15/69 (22)	66/604 (11)	81/673 (12)	19/328 (6)	47/276 (17)
Was a stool sample sent for stool culture/PCR within 48 hours of admission?	Yes. Excludes 'Not applicable'	45/66 (68)	418/572 (73)	463/638 (73)	219/315 (70)	199/257 (77)
Was stool sample positive?	Yes	1/45 (2)	18/418 (4)	19/463 (4)	6/219 (3)	12/199 (6)
Was stool sample sent for *C. difficile* toxin within 48 hours of admission?	Yes. Excludes 'Not applicable'	35/65 (54)	383/565 (68)	418/630 (66)	197/310 (64)	186/255 (73)
Stool sample positive for *C. difficile* toxin	Yes	1/35 (3)	15/383 (4)	16/418 (4)	10/197 (5)	5/186 (3)
Flexible sigmoidoscopy or colonoscopy within 24 hours of admission?	Yes. Excludes 'Not applicable'	12/57 (21)	176/478 (37)	188/535 (35)	55/247 (22)	121/231 (52)
Flexible sigmoidoscopy or colonoscopy between 24 to 72 hours after admission?	Yes. Excludes 'Not applicable'	13/45 (29)	90/294 (31)	103/339 (30)	50/188 (27)	40/106 (38)
Were biopsies taken for histology?	Yes	13/13 (100)	85/90 (94)	98/103 (95)	48/50 (96)	37/40 (93)
Were biopsies taken for cytomegalovirus?	Yes	3/13 (23)	43/85 (51)	46/98 (47)	22/48 (46)	21/37 (57)
Imaging used during the admission:						
None		33/69 (48)	128/604 (21)	161/673 (24)	82/328 (25)	46/276 (17)
Abdominal X-ray		22/69 (32)	364/604 (60)	386/673 (57)	171/328 (52)	193/276 (70)
Abdominal ultrasound		11/69 (16)	29/604 (5)	40/673 (6)	16/328 (5)	13/276 (5)
Abdominal CT scan		5/69 (7)	123/604 (20)	128/673 (19)	76/328 (23)	47/276 (17)
Other		13/69 (19)	168/604 (28)	181/673 (27)	92/328 (28)	76/276 (28)
Other details: Chest X-ray				125/181		

Ulcerative colitis	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Care team and ward						
Which specialty was responsible for the patient's care 24 hours after admission?	Acute or general medicine	2/69 (3)	43/602 (7)	45/671 (7)	34/326 (10)	9/276 (3)
	General surgery	8/69 (12)	23/602 (4)	31/671 (5)	20/326 (6)	3/276 (1)
	Gastroenterology	52/69 (75)	463/602 (77)	515/671 (77)	242/326 (74)	221/276 (80)
	Colorectal surgery	1/69 (1)	63/602 (10)	64/671 (10)	25/326 (8)	38/276 (14)
	Other	6/69 (9)	10/602 (2)	16/671 (2)	5/326 (2)	5/276 (2)
Was a gastroenterology consultant or registrar consulted? (excludes 'Not documented')	Yes	63/69 (91)	527/602 (88)	590/671 (88)	283/326 (87)	244/276 (88)
	No	4/69 (6)	44/602 (7)	48/671 (7)	28/326 (9)	16/276 (6)
	Not required	1/69 (1)	28/602 (5)	29/671 (4)	13/326 (4)	15/276 (5)
Was a colorectal (adult) or paediatric surgical consultant or registrar consulted? (excludes 'Not documented')	Yes	25/69 (36)	228/602 (38)	253/671 (38)	108/326 (33)	120/276 (43)
	No	27/69 (39)	203/602 (34)	230/671 (34)	132/326 (40)	71/276 (26)
	Not required	15/69 (22)	144/602 (24)	159/671 (24)	61/326 (19)	83/276 (30)
An IBD nurse specialist saw the patient during admission	Yes	16/69 (23)	103/602 (17)	119/671 (18)	18/326 (6)	85/276 (31)
Was the patient cared for on a specialist gastroenterology ward?	Yes	20/69 (29)	407/602 (68)	427/671 (64)	191/326 (59)	216/276 (78)
Gastroenterology ward type	Medical	12/20 (60)	151/407 (37)	163/427 (38)	83/191 (43)	68/216 (31)
	Joint medical/surgical	6/20 (30)	212/407 (52)	218/427 (51)	91/191 (48)	121/216 (56)
	Surgical	2/20 (10)	44/407 (11)	46/427 (11)	17/191 (9)	27/216 (13)
Was psychological support provided?	Yes	17/69 (25)	57/602 (9)	74/671 (11)	33/326 (10)	24/276 (9)
	Yes. If patient had a comorbidity of psychological condition			16/77 (21)		

Ulcerative colitis	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Psychological support provided by:						
Psychologist		4/17 (24)	9/57 (16)	13/74 (18)	5/33 (15)	4/24 (17)
Psychiatrist		1/17 (6)	15/57 (26)	16/74 (22)	10/33 (30)	5/24 (21)
Social worker		11/17 (65)	28/57 (49)	39/74 (53)	13/33 (39)	15/24 (63)
Pastoral		1/17 (6)	8/57 (14)	9/74 (12)	5/33 (15)	3/24 (13)
Other		4/17 (24)	6/57 (11)	10/74 (14)	4/33 (12)	2/24 (8)
Did the patient receive short-term psychotropic medication?	Yes. Excludes 'Not applicable'	1/67 (1)	80/530 (15)	81/597 (14)	44/308 (14)	36/222 (16)
Was patient discussed at a multidisciplinary team meeting?	Yes. If non-elective patient	9/61 (15)	51/551 (9)	60/612 (10)	17/300 (6)	34/251 (14)
Medical intervention						
Use of antithrombotic therapy						
Was the patient given prophylaxis for deep vein thrombosis and pulmonary embolism?	Yes	21/69 (30)	494/601 (82)	515/670 (77)	264/326 (81)	230/275 (84)
No	No	48/69 (70)	102/601 (17)	150/670 (22)	57/326 (17)	45/275 (16)
	Contraindicated	0/69 (0)	5/601 (1)	5/670 (1)	5/326 (2)	0/275 (0)
Did the patient have a thrombotic episode during this admission?	Yes	0/61 (0)	3/551 (1)	3/612 (<1)	2/300 (1)	1/251 (<1)
Thrombotic episode - type	Deep vein thrombosis, if non-elective patient	0/0	1/3 (33)	1/3 (33)	0/2 (0)	1/1 (100)
	Pulmonary embolism, if non-elective patient	0/0	2/3 (67)	2/3 (67)	2/2 (100)	0/1 (0)
	Other, if non-elective patient	0/0	0/3 (0)	0/3 (0)	0/2 (0)	0/1 (0)
Steroid and other therapy						
Were corticosteroids initiated during this admission?	Yes. If non-elective patient	47/61 (77)	464/551 (84)	511/612 (83)	260/300 (87)	204/251 (81)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
Corticosteroid route of administration:		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Intravenous		41/47 (87)	405/464 (87)	446/511 (87)	224/260 (86)	181/204 (89)
Oral		12/47 (26)	262/464 (56)	274/511 (54)	156/260 (60)	106/204 (52)
Topical		1/47 (2)	32/464 (7)	33/511 (6)	17/260 (7)	15/204 (7)
Other therapies started during the admission (if non-elective patient)						
None		25/61 (41)	162/553 (29)	187/614 (30)	102/302 (34)	60/251 (24)
5-aminosalicylates		17/61 (28)	203/553 (37)	220/614 (36)	106/302 (35)	97/251 (39)
Thiopurine		9/61 (15)	115/553 (21)	124/614 (20)	58/302 (19)	57/251 (23)
Methotrexate		0/61 (0)	8/553 (1)	8/614 (1)	2/302 (1)	6/251 (2)
Cyclosporin		0/61 (0)	15/553 (3)	15/614 (2)	6/302 (2)	9/251 (4)
Anti-TNF		8/61 (13)	94/553 (17)	102/614 (17)	42/302 (14)	52/251 (21)
Nutrition		8/61 (13)	36/553 (7)	44/614 (7)	21/302 (7)	15/251 (6)
Other		17/61 (28)	96/553 (17)	113/614 (18)	47/302 (16)	49/251 (20)
Other details: Antibiotics				64/113		
Surgical intervention						
Did the patient have surgery on this admission?	Yes	11/69 (16)	96/602 (16)	107/671 (16)	42/326 (13)	54/276 (20)
Was there a delay of more than 48 hours between decision to operate and surgery for non-elective patients?	Yes. Excludes 'Unclear'	0/2 (0)	6/37 (16)	6/39 (15)	4/14 (29)	2/23 (9)
Reason for surgery delay	Ulcerative colitis Improvement	0/0	0/6 (0)	0/6 (0)	0/4 (0)	0/2 (0)
	Cancelled - resource reasons	0/0	2/6 (33)	2/6 (33)	1/4 (25)	1/2 (50)
	Cancelled - clinical reasons	0/0	0/6 (0)	0/6 (0)	0/4 (0)	0/2 (0)
	Patient declined	0/0	1/6 (17)	1/6 (17)	1/4 (25)	0/2 (0)
	Unclear	0/0	1/6 (17)	1/6 (17)	1/4 (25)	0/2 (0)
	Other	0/0	2/6 (33)	2/6 (33)	1/4 (25)	1/2 (50)
Was the ASA status recorded on an anaesthetic chart?		6/11 (55)	74/95 (78)	80/106 (75)	34/42 (81)	40/53 (75)

Ulcerative colitis			Age (years)			Partial IBD Service (18 years and over)	
			Under 18	18 and over	All	No	Yes
			n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
What was the ASA status value?							
	1	Excludes 'Not applicable'	0/6 (0)	6/73 (8)	6/79 (8)	5/34 (15)	1/39 (3)
	2	Excludes 'Not applicable'	5/6 (83)	38/73 (52)	43/79 (54)	11/34 (32)	27/39 (69)
	3	Excludes 'Not applicable'	1/6 (17)	28/73 (38)	29/79 (37)	17/34 (50)	11/39 (28)
	4	Excludes 'Not applicable'	0/6 (0)	1/73 (1)	1/79 (1)	1/34 (3)	0/39 (0)
What were the indications for surgery?							
Obstruction			0/11 (0)	2/96 (2)	2/107 (2)	1/42 (2)	1/54 (2)
Perforation			0/11 (0)	6/96 (6)	6/107 (6)	3/42 (7)	3/54 (6)
Abscess			0/11 (0)	8/96 (8)	8/107 (7)	6/42 (14)	2/54 (4)
Ileostomy formation			1/11 (9)	11/96 (11)	12/107 (11)	8/42 (19)	3/54 (6)
Stoma closure			1/11 (9)	5/96 (5)	6/107 (6)	2/42 (5)	3/54 (6)
Medical therapy fail			5/11 (45)	44/96 (46)	49/107 (46)	18/42 (43)	26/54 (48)
Toxic megacolon			0/11 (0)	4/96 (4)	4/107 (4)	2/42 (5)	2/54 (4)
Bleeding			3/11 (27)	6/96 (6)	9/107 (8)	2/42 (5)	4/54 (7)
Completion proctectomy			3/11 (27)	22/96 (23)	25/107 (23)	13/42 (31)	9/54 (17)
Dysplasia			0/11 (0)	5/96 (5)	5/107 (5)	1/42 (2)	4/54 (7)
Cancer			0/11 (0)	1/96 (1)	1/107 (1)	0/42 (0)	1/54 (2)
Other			1/11 (9)	14/96 (15)	15/107 (14)	8/42 (19)	6/54 (11)
Type of intervention:							
Proctocolectomy			2/11 (18)	20/96 (21)	22/107 (21)	4/42 (10)	16/54 (30)
Subtotal colectomy			3/11 (27)	25/96 (26)	28/107 (26)	10/42 (24)	15/54 (28)
Completion proctectomy			2/11 (18)	18/96 (19)	20/107 (19)	13/42 (31)	5/54 (9)
Formation of ileal pouch-anal anastomosis			5/11 (45)	23/96 (24)	28/107 (26)	12/42 (29)	11/54 (20)
Formation of ileostomy			5/11 (45)	44/96 (46)	49/107 (46)	20/42 (48)	24/54 (44)
Revision of stoma			2/11 (18)	1/96 (1)	3/107 (3)	0/42 (0)	1/54 (2)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Closure of stoma		1/11 (9)	2/96 (2)	3/107 (3)	0/42 (0)	2/54 (4)
Abscess drainage		0/11 (0)	6/96 (6)	6/107 (6)	3/42 (7)	3/54 (6)
Division of adhesions		1/11 (9)	6/96 (6)	7/107 (7)	5/42 (12)	1/54 (2)
Perineal procedure		0/11 (0)	1/96 (1)	1/107 (1)	1/42 (2)	0/54 (0)
Other		3/11 (27)	25/96 (26)	28/107 (26)	13/42 (31)	12/54 (22)
Was the surgery done laparoscopically or laparoscopic assisted?	Yes	8/11 (73)	41/95 (43)	49/106 (46)	12/42 (29)	29/53 (54)
	No	3/11 (27)	50/95 (52)	53/106 (50)	27/42 (64)	23/53 (43)
	Unclear	0/11 (0)	4/95 (4)	4/106 (4)	3/42 (7)	1/53 (2)
Was the patient seen by a stoma nurse during this admission?*	Yes	11/11 (100)	70/79 (89)	81/90 (90)	31/32 (97)	39/47 (83)
	No	0/11 (0)	5/79 (6)	5/90 (6)	1/32 (3)	4/47 (9)
	Unclear	0/11 (0)	4/79 (5)	4/90 (4)	0/32 (0)	4/47 (9)
Was the patient seen by a stoma nurse before surgery?*	Yes	7/11 (64)	57/79 (72)	64/90 (71)	22/32 (69)	35/47 (74)
	No	2/11 (18)	9/79 (11)	11/90 (12)	4/32 (13)	5/47 (11)
	Unclear	2/11 (18)	13/79 (16)	15/90 (17)	6/32 (19)	7/47 (15)
*Excludes strictureplasty, abscess drainage, perineal procedure, adhesion division, seton insertion, other						
Surgical complications						
Did the patient develop postoperative complications? (Only includes patients that had surgery)		4/11 (36)	38/95 (40)	42/106 (40)	11/42 (26)	27/53 (51)
Wound infection		0/11 (0)	7/96 (7)	7/107 (7)	2/42 (5)	5/54 (9)
Rectal stump complications		1/11 (9)	4/96 (4)	5/107 (5)	0/42 (0)	4/54 (7)
Intra-abdominal bleeding		0/11 (0)	0/96 (0)	0/107 (0)	0/42 (0)	0/54 (0)
Intra-abdominal abscess		0/11 (0)	3/96 (3)	3/107 (3)	0/42 (0)	3/54 (6)
Anastomotic leakage		0/11 (0)	1/96 (1)	1/107 (1)	0/42 (0)	1/54 (2)
Stoma complications		1/11 (9)	1/96 (1)	2/107 (2)	1/42 (2)	0/54 (0)
Deep vein thrombosis (DVT)		0/11 (0)	0/96 (0)	0/107 (0)	0/42 (0)	0/54 (0)
Pulmonary embolism (PE)		0/11 (0)	1/96 (1)	1/107 (1)	1/42 (2)	0/54 (0)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Small bowel obstruction		1/11 (9)	0/96 (0)	1/107 (1)	0/42 (0)	0/54 (0)
Ileus		1/11 (9)	10/96 (10)	11/107 (10)	1/42 (2)	9/54 (17)
Total parenteral nutrition (TPN)		2/11 (18)	8/96 (8)	10/107 (9)	3/42 (7)	5/54 (9)
Cardiac		0/11 (0)	4/96 (4)	4/107 (4)	2/42 (5)	2/54 (4)
Respiratory		0/11 (0)	4/96 (4)	4/107 (4)	1/42 (2)	3/54 (6)
Clostridium difficile-associated diarrhoea		0/11 (0)	1/96 (1)	1/107 (1)	0/42 (0)	1/54 (2)
Malnutrition		2/11 (18)	5/96 (5)	7/107 (7)	1/42 (2)	4/54 (7)
Reoperation (for any reason)		0/11 (0)	6/96 (6)	6/107 (6)	3/42 (7)	3/54 (6)
Other		1/11 (9)	10/96 (10)	11/107 (10)	3/42 (7)	7/54 (13)
Anaemia						
Was the patient anaemic on admission?	Yes	29/69 (42)	233/601 (39)	262/670 (39)	117/326 (36)	116/275 (42)
	No	37/69 (54)	348/601 (58)	385/670 (57)	197/326 (60)	151/275 (55)
	Not recorded	3/69 (4)	20/601 (3)	23/670 (3)	12/326 (4)	8/275 (3)
Was the anaemia noted or commented on by the treating team?	Yes	20/29 (69)	149/233 (64)	169/262 (65)	80/117 (68)	69/116 (59)
	No	9/29 (31)	84/233 (36)	93/262 (35)	37/117 (32)	47/116 (41)
	Not recorded	0/29 (0)	0/233 (0)	0/262 (0)	0/117 (0)	0/116 (0)
Was anaemia at presentation due to iron deficiency?	Yes	18/29 (62)	100/233 (43)	118/262 (45)	51/117 (44)	49/116 (42)
	No	4/29 (14)	33/233 (14)	37/262 (14)	17/117 (15)	16/116 (14)
	Other cause/uncertain	1/29 (3)	28/233 (12)	29/262 (11)	15/117 (13)	13/116 (11)
	Not recorded	6/29 (21)	72/233 (31)	78/262 (30)	34/117 (29)	38/116 (33)
What treatment was administered for anaemia?						
Oral iron		1/18 (6)	6/100 (6)	7/118 (6)	4/51 (8)	2/49 (4)
Intravenous iron		11/18 (61)	75/100 (75)	86/118 (73)	38/51 (75)	37/49 (76)
Blood transfusion		4/18 (22)	19/100 (19)	23/118 (19)	13/51 (25)	6/49 (12)
Nutritional advice		1/18 (6)	6/100 (6)	7/118 (6)	4/51 (8)	2/49 (4)
Not recorded		4/18 (22)	15/100 (15)	19/118 (16)	5/51 (10)	10/49 (20)

Ulcerative colitis	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Discharge arrangements						
Was the patient taking oral steroids on discharge?	Yes	49/67 (73)	464/571 (81)	513/638 (80)	254/304 (84)	210/267 (79)
	No	18/67 (27)	101/571 (18)	119/638 (19)	50/304 (16)	51/267 (19)
	Not applicable	0/67 (0)	6/571 (1)	6/638 (1)	0/304 (0)	6/267 (2)
For those on steroids was steroid reduction program stated on discharge?	Yes	38/49 (78)	406/464 (88)	444/513 (87)	214/254 (84)	192/210 (91)
	No	11/49 (22)	50/464 (11)	61/513 (12)	39/254 (15)	11/210 (5)
	Not applicable	0/49 (0)	8/464 (2)	8/513 (2)	1/254 (0)	7/210 (3)
For those on steroids were bone protection agents prescribed?	Yes	9/49 (18)	127/464 (27)	136/513 (27)	69/254 (27)	58/210 (28)
	No	39/49 (80)	327/464 (70)	366/513 (71)	183/254 (72)	144/210 (69)
	Not applicable	1/49 (2)	10/464 (2)	11/513 (2)	2/254 (1)	8/210 (4)
Was ongoing nutritional supplementation recommended on discharge?	Yes	17/67 (25)	152/572 (27)	169/639 (26)	75/305 (25)	77/267 (29)
	No	49/67 (73)	356/572 (62)	405/639 (63)	210/305 (69)	146/267 (55)
	Not applicable	1/67 (1)	64/572 (11)	65/639 (10)	20/305 (7)	44/267 (16)
Were arrangements made for follow-up by a dietitian?	Yes	13/67 (19)	91/572 (16)	104/639 (16)	41/305 (13)	50/267 (19)
	No	53/67 (79)	407/572 (71)	460/639 (72)	237/305 (78)	170/267 (64)
	Not applicable	1/67 (1)	74/572 (13)	75/639 (12)	27/305 (9)	47/267 (18)
	Yes. If they had ongoing nutritional supplementation recommended.	7/17 (41)	67/152 (44)	74/169 (44)	26/75 (35)	41/77 (53)
Was the patient on immunosuppressive drugs on discharge?	Yes	34/67 (51)	268/572 (47)	302/639 (47)	142/305 (47)	126/267 (47)
	No	33/67 (49)	289/572 (51)	322/639 (50)	157/305 (51)	132/267 (49)
	Not applicable	0/67 (0)	15/572 (3)	15/639 (2)	6/305 (2)	9/267 (3)
Was a plan for safety monitoring of immunosuppressive drugs implemented?	Yes	18/34 (53)	174/268 (65)	192/302 (64)	80/142 (56)	94/126 (75)
Was there a plan for maintenance anti-TNF on discharge?	Yes	11/67 (16)	89/572 (16)	100/639 (16)	44/305 (14)	45/267 (17)
	No	49/67 (73)	382/572 (67)	431/639 (67)	195/305 (64)	187/267 (70)
	Not applicable	7/67 (10)	101/572 (18)	108/639 (17)	66/305 (22)	35/267 (13)

Ulcerative colitis	Extra information	Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was a plan for safety monitoring of anti-TNF implemented?	Yes	7/11 (64)	69/89 (78)	76/100 (76)	31/44 (70)	38/45 (84)
Patients discharged on oral steroids, immunosuppressive drugs or anti-TNF agents (derived)				537/673 (80)		
Were psychological and behavioural factors identified to contribute to poor disease management	Yes	6/67 (9)	31/572 (5)	37/639 (6)	19/305 (6)	12/267 (4)
	No	55/67 (82)	443/572 (77)	498/639 (78)	220/305 (72)	223/267 (84)
	Unclear	6/67 (9)	98/572 (17)	104/639 (16)	66/305 (22)	32/267 (12)
Was an outpatient psychological plan put in place?	Yes	4/6 (67)	20/31 (65)	24/37 (65)	13/19 (68)	7/12 (58)
Was a plan for follow up documented in the discharge summary?	Yes	63/67 (94)	542/572 (95)	605/639 (95)	289/305 (95)	253/267 (95)
Was discharge summary sent, faxed, emailed to the patient's general practitioner?	Yes	56/67 (84)	461/572 (81)	517/639 (81)	247/305 (81)	214/267 (80)
	No	4/67 (6)	19/572 (3)	23/639 (4)	7/305 (2)	12/267 (4)
	Unclear	7/67 (10)	92/572 (16)	99/639 (15)	51/305 (17)	41/267 (15)
Outpatient care before admission						
Patient had previous outpatient visits or private practice consultation for IBD	Yes	50/69 (72)	407/601 (68)	457/670 (68)	234/326 (72)	173/275 (63)
	No	17/69 (25)	137/601 (23)	154/670 (23)	62/326 (19)	75/275 (27)
	Unknown	2/69 (3)	57/601 (9)	59/670 (9)	30/326 (9)	27/275 (10)

Ulcerative colitis		Age (years)			Partial IBD Service (18 years and over)	
		Under 18	18 and over	All	No	Yes
		Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)
Number of times patient seen in 12 months before start date of this admission		N=39 4 (3, 5)	N=215 3 (1, 5)	N=254 3 (2, 5)	N=96 3 (1, 4)	N=119 3 (2, 5)
		n/N (%)	n/N (%)	n/N (%)	n/N (%)	n/N (%)
Was disease active at last outpatient department appointment or private practice review?	Yes	28/50 (56)	196/407 (48)	224/457 (49)	101/234 (43)	95/173 (55)

Note: Percentages may not sum exactly to 100%, where relevant, due to rounding.

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Appendixes

Appendix 1 Participating sites

The following sites provided data for the Clinical Audit and the Organisational Audit.

IBD Audit participating sites

ACT	Calvary Public Hospital
	Canberra Hospital #
NSW	Auburn Hospital
	Blacktown and Mount Druitt Hospital #
	Campbelltown Hospital #
	Concord Repatriation Hospital #
	Dubbo Hospital
	Griffith Base Hospital
	Hornsby Ku-ring-gai Health Service #
	John Hunter Hospital #
	Liverpool Hospital #
	Manly Hospital #
	Mona Vale Hospital #
	Royal North Shore #
	Royal Prince Alfred
	Shoalhaven Hospital
	St George Hospital #
	St Vincent's Hospital, Sydney #
	Sutherland Hospital #
	Sydney Children's Hospital (Randwick) #
	Sydney Children's Hospital (Westmead) #
	Tamworth Hospital #
	Westmead Hospital #
	Wollongong Hospital #
QLD	Bundaberg Hospital #
	Caboolture Hospital
	Cairns Hospital /Innisfail/Mossman #
	Gold Coast University Hospital #
	Hervey Bay and Maryborough Hospital #
	Lady Cilento Children's Hospital #
	Mareeba Hospital #
	Mater Adult Hospital #
	Nambour Hospital #

QLD	Princess Alexandra Hospital # Queen Elizabeth II Jubilee Hospital # Redcliffe Hospital Royal Brisbane and Women's Hospital # The Prince Charles Hospital Toowoomba Base Hospital
SA	Adelaide Women's and Children's Hospital # Flinders Medical Centre # Port Augusta Hospital # Royal Adelaide Hospital # The Lyell McEwin Hospital # The Queen Elizabeth Hospital Whyalla Hospital & Health Services
TAS	Royal Hobart Hospital
VIC	Albury Wodonga Health # Austin Hospital # Ballarat Health Services# Bendigo Hospital # Dandenong Hospital # Eastern Health (Box Hill/Maroondah) # Frankston Hospital Geelong Hospital # Goulburn Valley Hospital Mildura Base Hospital Monash Children's Hospital # Monash Health Casey Hospital Monash Medical Centre # Northern Hospital # Portland District Health # Royal Children's Hospital # Royal Melbourne Hospital # St Vincent's Hospital, Melbourne # The Alfred Hospital # West Gippsland Healthcare Group # Western Hospital Footscray #
WA	Bunbury Hospital Rockingham General Hospital Sir Charles Gairdner Hospital #

# denotes participation in both the Organisational and Clinical Audits.

Appendix 2 Survey questions

Full text survey questions for the Organisational Audit and Clinical Audit are available in PDF format at: www.crohnsandcolitis.com.au

There are four separate sets of survey questions:

- Organisational survey (paediatric) – used for specialist paediatric hospitals
- Organisational survey (adult) – used for all other hospitals
- Clinical Crohn's disease survey – adult and paediatric variants
- Clinical ulcerative colitis survey – adult and paediatric variants

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