Crohn's & Colitis Australia

Inflammatory Bowel Disease Paediatric Quality of Care

Hospital Audit 2023

Research Report

About CCA

Crohn's & Colitis Australia's primary purpose is to improve quality of life by helping people understand, respond to and actively manage their care. On the journey to finding a cure, Crohn's & Colitis Australia's ambition is to empower and support the IBD community- encouraging innovation, advancing quality of care and facilitating new knowledge informed by deeper research. Fundamentally, Crohn's & Colitis Australia is an advocate and an educator, leading tough conversations about taboo topics.

For more than three decades, Crohn's & Colitis Australia has been empowering the more than 100,000 Australian men, women and children living with Crohn's disease or ulcerative colitis – collectively known as IBD – to live fearlessly because in fearlessness, there is strength.

Visit www.crohnsandcolitis.org.au for more information about this report or CCA's programs and support services.

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Version 1.2 updated 16 May 2024

Contents

Acknowledgements

Crohn's & Colitis Australia (CCA) would like to thank the hundreds of young people living with IBD, their parents and carers who are the subject of this audit.
Special thanks go to staff and auditors at the eight participating hospitals who contributed to the audit by providing survey and clinical audit data and participated in ethical approval processes.
CCA gratefully acknowledges those that have provided expert support to the project through the Project Advisory Committee lead by Dr Edward Giles and by providing contributions that support the work of this committee.

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Thanks also to Joanna Maggs Human Research Ethics Coordinator Monash Health and Gauravi Gawade, CCA volunteer for their support of the project.

This project has been funded through the support of the Australian Government Department of Health.

Executive Summary

Abdominal pain, diarrhoea, urgency to have a bowel movement, fever and rectal bleeding are alarming symptoms for any person. For young people living with inflammatory bowel disease (IBD) these symptoms can develop on any day, during school, a cricket game, dance class or a date. Weight loss, anaemia, persistent fatigue, malnutrition, delayed growth and puberty occur in children and adolescents with IBD. The social stigma and psychological affect have a broader impact on their wellbeing and societal participation. Crohn's disease (CD) and ulcerative colitis (UC), the main forms of IBD are chronic, lifelong gastrointestinal disorders affecting at least 100,000 Australians.[1] Between 8-10% of IBD is diagnosed before the age of 18 years.[2,3] Annual hospital costs, productivity losses, indirect and economic costs of IBD management to the Australian public were estimated at over $3.1 billion in 2013 and likely to be higher now.[1]

"He cried a lot in toilet and he was just feeling… Like he loved to play soccer and at one stage he was not feeling like he's gonna play soccer at all one day. He was thinking he like his life is almost gone and it's, it's, really like heartbreaking for parents for mum and dad both."

– Mother of a 9-year-old living with ulcerative colitis

Quality of care for young people (less than 18years) with IBD is variable and a hospital audit in 2016 identified hospitals across Australia did not meet the specified standards.[4] This project lead by Crohn's & Colitis Australia (CCA) with assistance from the Gastroenterological Society of Australia (GESA) undertook to re-audit the organisation, resources and delivery of hospital care to young people with IBD (Hospital Audit) and identify changes since 2016. Hospitals nationally were invited to participate in an online survey of the organisation and resources of care and conduct clinical audit of inpatient overnight admissions for 2021. Concurrently, CCA completed survey of the patient experience of the quality of care for young people with IBD (IBD Paediatric Patient Experience Survey).

Findings

Nationally, eight hospitals participated in the Hospital Audit examining 186 admissions, almost a quarter (23%) of all public hospital admissions for IBD patients in 2021.

Australian Institute of Health and Welfare data indicates that while national Crohn's disease overnight admissions were steady, ulcerative colitis admissions in 2021 increased by 92% from 2014.

Public hospitals provided 91% of overnight admissions, private hospitals 9%. Admissions occurred in major city hospitals for most (87%). This centralised model shows only a few areas of improving data since 2014, though there are many areas where care of children with IBD continues to fall below standard.

Profound
care for children with high burden of disease

Young people admitted to hospital are unwell with active disease commonly recorded at the previous outpatient attendance (63%) and anaemia present in half (49%). Of those admitted to hospital, half (47%) had an admission in the previous 2 years. For youth with CD, median C-reactive protein level was 52 indicating high severity of inflammation and malnutrition was recorded as present in (37%).

Children and adolescents were most commonly admitted as emergency admissions (45%) which is supported by national AIHW data (68%). Only 2-7% of people were referred into hospital after consultation with an IBD helpline. Indeed, helpline availability was less than in 2014 down from 6/6 to 6/8 sites in 2021 despite evidence of such care reducing GP, outpatient and emergency attendance.[5]

Clearly, active disease is not being resolved in the ambulatory setting resulting in deterioration and unplanned admission of youth in a severe state of illness – a reactive care model.

Limited multidisciplinary care

The National Strategic Framework for Chronic Conditions recognises the importance of access to and continuity of care involving the multidisciplinary team.[6] Multidisciplinary team access continues to evade youth with IBD: only 23% of CD inpatients were seen by an IBD nurse, compared with 33% in 2014 reducing opportunity for continuity of care and better care management. Admissions noted psychological comorbidity in 28% cases and yet psychologists were not part of the team at any site which is a reduction on the one site that did in 2014.

Clinical gaps

Important preventive anti-thrombotic use is lower in hospital despite new clinical guidelines that reinforce its use (10% in 2021 down from 30% in 2014 ($p<0.001$)).[7] Use of investigative stool samples (important in guiding inpatient management) remains low (e.g. 64% in 2021 vs 68% in 2014).

The most prescribed medications were aminosalicylates, anti-TNFs and corticosteroids. IBD medications listed on the Pharmaceutical Benefits Scheme are limited for youth compared with adults. Hospital sites reported that use of new, off-label IBD medications occurred for 56 young people.

The increased proportion of UC admissions were mostly (70%) patients that had been seen in outpatient clinic, and 62% had known active disease. Potentially increased access to multidisciplinary care and a greater range of newer medicines which are available to adults with IBD could support escalated therapy as an outpatient to decrease the need for hospital admissions.

Improving outcomes

IBD-related surgery has not increased in 2021 compared with 2014 with CD steady and UC surgical admissions reduced to 5% in 2021 from 16% in 2014 ($p<0.05$). The reduced UC surgery has occurred despite large increase in UC admissions overall, probably indicating improved use of rescue medications, although access remains limited (noting 56 IBD patients were treated with off-label medications).

The use of corticosteroids, which have harmful cumulative side effects, for more than 3 months in the year prior to admission has reduced to 1% from 10% in 2014. This is one of the few positive findings, but the 56 patients needing off-label medications shows that IBD services are having to work around the system to find alternatives to steroid therapy.

The patient perspective: IBD Patient Experience Survey 2023

Patient experience is positively associated with clinical effectiveness and health care safety and therefore is an essential pillar in measuring quality of care.[8] As described in the introduction, a study of the patient and parent/carer perspective of the quality of care for young people with IBD was concurrently completed. The full report of this national study is reported at https://crohnsandcolitis.org.au/advocacy/our-projects/ibd-paediatric-quality-of-care/.

The findings of the Patient Experience Survey complement the results of the Hospital Audit. Important findings of the Patient Experience Survey can be summarised as follows:

- Youth living with IBD are confronted with a high disease burden
- IBD can impose a profound psychological burden on young people
- Families want care that extends beyond their primary specialist
- Care that is not tailored to the needs of young people
- Important information about managing IBD is often provided, but opportunities for education in key areas remain.
- Access to prompt advice, specialist review, and procedures is lacking.

These findings are merged with the Hospital Audit results to influence the recommendations to improve the quality of care for young people with IBD described in the Recommendations section.

Recommendations

Recommendation 1 - Improve mental health support

In recognition of the mental health burden of disease shown across this audit and also in the Patient Experience survey and family interviews:

a. **Support youth and family adjustment after diagnosis and prevention of mental health conditions**
b. **Increase access to therapeutic services for young people who develop mental health conditions**

*Rationale: Funding needs to be targeted to providing **disease-specific** psychological support within the IBD team. While greater access to mental health support may be a general priority, IBD patients suffer particular stressors that require an understanding of those challenges (e.g. toilet issues, medication, surgery, stoma bags etc.) Routine screening of mental health should be resourced.*

Recommendation 2 - Increase support for the multidisciplinary team

Resource gaps in centres of excellence should be addressed to support delivery of chronic disease care through provision of : IBD nurses (including helpline support), dietitians, pharmacists and psychologists.

Rationale: Given the current activity-based funding of hospitals where paediatric IBD units are based, there is no mechanism or incentive at State-level to provide these services. We believe there needs a new funding model to provide patient-centred multi-disciplinary care over wide geographic areas.
Gaps in responsiveness of care identified through patient experience and high emergency admission rates can be addressed through helplines and tertiary preventive care staffed by the multidisciplinary team.
Better access to paediatric specific care for those in regional and rural areas is needed and can be achieved through shared care models with metro specialist centres.

Recommendation 3 - Streamline access to newer medications

Regulatory processes and criteria for paediatric drug approval require change to increase equitable access to advanced therapies and potentially reduce hospitalisations.

Rationale: Paediatric patients have the most severe disease and arguably the most to lose with uncontrolled disease leading to lasting effects on growth, development, education and employment. Yet paediatric patients cannot access the same medications as adults with the same condition. Australia is an outlier in this compared to other developed countries. In addition streamlined access to escalated dose therapies to optimise drug efficacy, which is accepted as a strategy worldwide, but not allowed on the PBS should be introduced.

Recommendation 4 - Improved Pre-diagnosis experience

The experience of pre diagnosis care should be improved through rapid identification of symptoms in primary care and referral to specialist care.

Rationale: The consumer experience of delayed diagnosis and loss of confidence in the health care system creates dissatisfaction, and potential for disease progression. Greater awareness among primary care and community about warning signs for IBD may reduce lost opportunity for treatment.

Background and method

Inflammatory bowel disease (IBD) is estimated to affect 100,000 people in Australia, with evidence that its prevalence is increasing locally and globally.[1,9] Hospital costs, productivity losses and indirect expenses of IBD management to the Australian public are estimated to exceed $3.1 billion annually.[1] The disease is characterised by chronic, unpredictable, and often debilitating symptoms, including abdominal pain, bloody diarrhoea, frequent bowel movements (up to 20 - 30 per day), fatigue, weight loss, and anaemia. IBD most commonly emerges in early adulthood but can occur at any age and often before adulthood. Between 8-10% of IBD cases are diagnosed in children and adolescents before the age of 18 years, potentially affecting growth, puberty, education and psychosocial development.[2,3]

The increasing incidence and prevalence of IBD in young people confers a need for additional services for this patient group and specific attention to the investment, planning and specialist services provided to this age group.[9] The Final Report of the first audit of the organisation and provision of IBD services in Australia 2016 identified that the quality of care is variable for young people and fell well short of the national standards.[4,10] The report identified inconsistent access to multidisciplinary services, including psychological care, and deficiencies in important IBD care processes. This included attention to the equity of access to the new therapeutic agents, which have become a mainstay of treatment in adult patients but remain out of reach for many in the paediatric population.

In 2019 the Australian Government published the IBD National Action Plan,[11] which lists as its fifth priority the need for an audit of the quality of care for children, including a survey of the patient and family experience of care. CCA undertook this two-year project to:

1. Measure the patient experience of the quality of care for young people with IBD (IBD Paediatric Patient Experience Survey)
2. Audit the organisation, resources and delivery of hospital care to young people with IBD (Hospital Audit)

The first stage of the project, the IBD Paediatric Patient Experience survey, is complete and is referenced later in this report. The second stage, the Hospital Audit is the subject of this report.

Methodology

Eligible public and private hospital sites were identified from the Australian Institute of Health and Welfare's hospital listings. Psychiatric and women's (maternity care) hospitals were excluded, as were hospitals in very remote location, aged-care facilities, and rehabilitation centres. Data for the 2021 calendar year were collected via a webtool that allowed sites to complete a one-time survey of organisation-level activities and resourcing (Organisational Survey) and health record audit of a series of overnight patient admissions for Crohn's disease and ulcerative colitis (including IBD unspecified) identified via relevant ICD-10AM codes (Clinical Audit).

An additional dataset of national hospital admission and surgical procedure characteristics was provided by the Australian Institute of Health and Welfare National Hospital Morbidity database, 2020-21, and National Hospital Morbidity database, 2021-22.

Ethical approval was granted by the Monash Human Research Ethics Committee under the National Mutual Acceptance framework (HREC: RES-22-0000-050L). Site-specific authorisations were obtained from participating sites' respective research governance bodies. Project oversight was administered by the Paediatric IBD Quality of Care Project Advisory Committee (PAC) led by Dr Edward Giles and comprised of key provider and consumer stakeholders (listed on p.3 Acknowledgements). The PAC overseen by CCA's Scientific, Medical and Quality of Care Advisory Committee that reports to the Board of CCA.

It should be noted that the data collection period, 2021, was a year when some states/territories were experiencing continued restrictions and changes to hospital services associated with the COVID-19 pandemic.

Findings

Participation and national scope

Of the 241 public and private hospitals invited, eight public hospital sites (Appendix 1) across five states and territories participated in the audit. Except for one inner-regional site, all were designated as major city localities under the Australian Statistical Geographical Standard. Clinical audit data comprised 23% of national overnight Crohn's disease and ulcerative colitis public hospital admissions among youth aged <18 years (Table 1) as identified through Australian Institute of Health and Welfare data. Total IBD overnight acute hospital admissions for 2021 were 892, (public hospital 813, private hospital 79). Further national AIHW data available in Appendix 2.

Table 1 Clinical Audit sample as proportion of national AIHW reported public admissions (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021 and December 2013-November 2014)

	2021	2014
IBD national overnight admissions AIHW (N)	813	590
CCA IBD Hospital Audit (n,% national)	186 (23%)	144 (24%)

The following section describes combined findings from the Organisational Survey and Clinical Audit data. Complete results for the Organisational Survey, and Crohn's disease and Ulcerative colitis Clinical Audit, are presented in Appendix 3 and 4 respectively.
All results shown in Appendix 3 and 4 are provided with reference to the corresponding IBD Hospital Audit Report 2016 results (data collected in 2014) where available. Generally changes in results from 2014 to 2021 were found to be not statistically significant. Where results are statistically significant they are denoted as such in the following text and in the Appendix tables.

Demographics - Clinical Audit cases

Of the 186 clinical cases audited 47 % had Crohn's disease, 53% ulcerative colitis, and 52% were male (Table 2). Mean age was 12 years which was 2 years younger than the 2014 audit sample. The 12-17 year age bracket was 19% ($p<0.01$) smaller in the CD group in 2021 than in 2014.

Table 2 Clinical Audit participant gender and age (source: CCA Hospital Audit)

	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)	Total n/N (%)
Male	43/87 (49)	53/99 (54)	96/186 (52)
Female	43/87 (49)	45/99 (46)	88/186 (47)
Other	1/87 (1)	1/99 (1)	2/186 (1)
Age on Admission (years)	Mean(SD) 12.1 (3.5)	Mean(SD) 12.3 (3.5)	
0-1	0/87 (0)	0/99 (0)	0/186 (0)
2-5	4/87 (5)	5/99 (5)	9/186 (5)
6-11	27/87 (31)	30/99 (30)	57/186 (31)
12-17	56/87 (64)	64/99 (65)	120/186 (65)

Burden of disease

Admission and readmission

Findings from clinical case data suggest a high admission and readmission burden. Emergency admissions comprised nearly half of IBD combined admissions (45%). Referral in via Helpline occurred in 2-7% of admissions. Previous admissions in the last 2 years were reported in almost half of all cases (47%), one-third of which recorded an admission in the 30 days prior (33%). Stays of one week or more were reported in over a quarter (28%) of all admissions. Overnight admissions were unplanned for 61% of IBD combined overnight admissions.

Disease activity and comorbidity

Active disease was recorded at the last assessment in well over half of admissions (63%) with a previous IBD-related outpatient/private practice consultation (i.e., 70%; median 3 past-year visits). Admissions noted psychological comorbidity in 28% cases and, where documented, anaemia almost half the time (49%).

Admissions for new diagnosis made up 30% of audited CD admissions. Perianal disease was present in 22% of youth with CD and median C-reactive protein level was 52 indicating high severity of disease. Malnutrition was present in 37%.

Similarly, 22% of UC admissions were for new diagnosis. Among those previously seen in outpatients for their UC (70%), 3 visits in 12 months was the median and 62% had active disease at the last appointment.

IBD related surgical procedures occurred for 14 admissions (CD) and 10 admissions (UC).

Audit-to-audit

There was a small increase (3%) in national (AIHW reported) Crohn's disease overnight admissions from 2014 (N = 361) to 2021 (N = 373). Ulcerative colitis admissions, in stark contrast, nearly doubled (92%). Emergency admissions still comprise nearly half of cases, readmissions especially in the prior 30 days remain high. Length of stay is trending towards shorter admissions in 2021 with a greater proportion of 1-2 day admissions and fewer 3-27 day admissions (Table 3).

Table 3 Overnight length of stay (source: CCA Hospital Audit)

Days	2021	2014
1-2	51/186 (27)	21/144 (15)
3-6	82/186 (44)	74/144 (51)
7-13	40/186 (22)	36/144 (25)
14-27	8/186 (4)	8/144 (6)
28+	5/186 (3)	5/144 (3)

Multidisciplinary care

Most sites (7/8) had a paediatric gastroenterologist on staff and, where required, almost all admissions involved consultation with a gastroenterology consultant or registrar (97%). Additional specialty care was nevertheless limited in several areas. Three of eight sites lacked a specialist IBD nurse and fewer than one-in-five overall IBD admissions involved consultation with one (19%). Dietitian consultation occurred for over half of admissions (54%) where applicable. Psychological conditions were the most common comorbidity in the clinical audit (28%), although none of the IBD services had a paediatric mental health clinician on staff. Short-term psychological support occurred in a third of admissions (34%), most typically through a social worker (57%). A quarter of sites did not have multidisciplinary meetings at which to discuss complex IBD cases. Where these did occur, none reported the semi-

regular attendance (i.e., *sometimes,* or *always*) of a paediatric mental health clinician and, respectively, half of sites for a paediatric gastroenterology dietitian and paediatric pharmacist.
Instruction to GPs about the need for annual review such as colorectal cancer surveillance, renal function and bone densitometry are rarely (12%) passed on after hospitalisation.
Audit-to-audit
Changes in clinical staffing were not statistically significant from audit to audit. Slight increase in IBD nurse FTE was noted but no change in other previously identified areas of concern (e.g., psychological support, dietetic consultation/nutritional support and pharmacy). It remains the case that no site provides a full IBD team as defined in the Australian IBD Standards 2016.[12]

Responsive care

A face-to-face specialist review of disease relapse was reported as available within two weeks at all sites and often within seven working days (6/8). Access to an IBD specialist nurse or doctor was less commonly available via phone (5/8) though access by email was more common (7/8).
Telephone clinic access for annual review was only offered at 3/8 sites.
IBD specific outpatient clinics were offered at 5/8 sites.

Treatment

Generally admissions for treatment remain predominantly medical with a small number of surgical admissions occurring.

Surgery
IBD related surgery requiring overnight admission in hospital occurred on 26 occasions nationally (AIHW). Participating sites reported 24 overnight surgical admissions for the same period indicating very few procedures occur outside of these sites.
All sites that perform ileo-anal pouch surgery (N=6) note that most surgery is undertaken by a paediatric surgeon in conjunction with adult colorectal surgeon.
Of the 17 audited surgical cases 41% were performed laparoscopically.

Medication
Among Crohn's disease cases audited, two-thirds were on treatment when admitted: anti-TNF (36%), Azathioprine (29%) and exclusive enteral nutrition (23%). Steroids were used for more than 3 months in the year prior to admission by only 1%, down from 10% in 2014.
Among ulcerative colitis cases audited, two-thirds were on treatment when admitted: oral 5-ASA (49%) oral corticosteroids (49%) anti-TNF (32%). Upon discharge 80% were taking oral steroids. Steroids were used for more than 3 months in the year prior to admission by 13% and among those 39% used bone protection which may reflect increasing evidence for lack of benefit.[13]
Immunomodulators are the most commonly used medications at most sites for Crohn's disease. The PBS listed biological medications infliximab and adalimumab have increased in use. This is supported by a parallel study of Pharmaceutical Benefits Scheme 10% data undertaken by CCA.[14] The use of new, off-label IBD medications is estimated to have occurred for 56 youth at across all participating sites in 2021.
Anti thrombotic therapy was given to just 10% of patients admitted overnight, significantly less ($p<0.05$) than in 2014. This is well below the international best practice standard requiring that even paediatric patients with acute severe colitis to be on thromboprophylaxis unless contraindicated.[7] No thrombotic episodes were recorded.
Audit-to-Audit
During the audit-to-audit period, AIHW data shows that no increase in surgery admissions occurred, despite the large increase in UC admissions.

For CD cases, Azathioprine ($p<0.01$) and oral 5-ASA ($p<0.05$) were used less in 2021 than 2014 in this sample. Steroids were used for more than 3 months in the year prior to admission by only 1%, down from 11% ($p<0.05$) in 2014.
For UC cases, Azathioprine ($p<0.01$) was used less in 2021 than 2014 in this sample.

Investigations
Stool culture was performed for 53% of patients with CD audited, 12% were positive. Stool sample for Clostridioidies difficile toxin was sent for 44% and 9% of those were identified to have clostridium difficile infection. For those with UC 64% were sent for stool culture, but just 48% sent for Clostridioidies difficile with a positive result of 7%. Abdominal X-ray for those admitted for UC was performed less often in 2021 than 2014 (17% vs 32% $p<0.05$).
Abdominal ultrasound was performed on 30% but the emerging preferred routine test intestinal ultrasound was only performed on 6% of those with CD.
Flexible sigmoidoscopy was carried out for only 22% of UC patients within the first 24 hours where applicable and a further 32% before 72 hours elapsed.
Of those with UC patients with biopsies taken for histology, only 60% had them checked for cytomegalovirus.

Assessment
PCDAI completed for 20% CD and PUCAI in just 59% UC.
Audit-to-Audit
Since 2014 there has been no change in the proportion of sites that have a policy / protocol for acute severe ulcerative colitis.
Faecal calprotectin results recorded within 24 hours of admission increased but were not statistically significant.

Documentation and quality review

Overall there was variable but generally inadequate documentation of clinical factors that were audited.
Smoking is one of the few modifiable behaviours that can impact inflammatory bowel disease, yet 92% of cases audited did not have smoking status documented.
Height was recorded in the first 2 days of admission in less than half (46%) of cases audited.
Hospitals describe good capability in relation to providing education, choice in care and opportunity to provide feedback on care. Generally opportunities for patients to contribute to service improvement are not adopted at sites: no site conducts patient satisfaction by survey or comment cards and only 1 site conducts annual review of their service.
Searchable databases or registries of paediatric IBD patients are held by most sites (8/8) though the extent of data included varied, only 2/6 update with all patients on immunosuppressives. Data on the percentage of patients who remain on steroids continuously for 3 months is only collected and reviewed at 2/8 sites.

Primary care interface

Referral guidance for GPs with symptomatic patients has been developed at 5/8 sites.
Discharge summaries are sent to GPs in most cases (88%). Participating sites report that they do not routinely give clear instruction to GPs about the need for annual review and assessment of colorectal cancer (0%), renal function (13%), bone densitometry 13%.

Appendix 1 - Participating Sites

The sites listed below provided data for the Organisational Survey and Clinical Audit.

Canberra Hospital (ACT)
Monash Children's Hospital (Vic)
John Hunter Children's Hospital (NSW)
Queensland Children's Hospital (QLD)
Royal Children's Hospital Melbourne (Vic)
Royal Hobart Hospital (Tas)
Women & Children's Hospital (SA)
The Children's Hospital at Westmead (NSW)

CCA would like to recognise the intent and efforts to participate by Perth Children's Hospital and Sydney Children's Hospital, Randwick who were unable to participate.

Appendix 2 - Australian Institute of Health and Welfare:

Acute hospital inpatient data Crohn's disease and ulcerative colitis 2021 (0-17 years)

NB All data shown is for Australian Public hospitals unless specified Private hospital.

National separations and clinical audit sample proportion (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021 and December 2013-November 2014)

	2021	2014
Crohn's disease national overnight admissions (N)	373	361
Crohn's disease CCA Hospital Audit (% national)	87 (23%)	75 (21%)
Ulcerative colitis national overnight admissions (N)	440	229
Ulcerative colitis CCA Hospital Audit (% national)	99 (23%)	69 (30%)

Overnight separations by gender 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Gender	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)	Total n/N (%)
Overnight	Male	196/373 (53)	212/440 (48)	408 (50)
Overnight	Female	177/373 (47)	228/440 (52)	405 (50)

Public and private hospital separations 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)	Total n/N (%)
Public Overnight	373 (46)	440 (54)	813 (100)
Public Sameday	4295 (71)	1737 (29)	6032 (100)
Private Overnight	40 (50)	39 (50)	79 (100)
Private Sameday	528 (54)	456 (46)	984 (100)

Surgical separations for selected IBD procedures 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Crohn's disease	Ulcerative colitis	Total
Public Overnight	13	13	26
Public Sameday	0	0	0
Private hospital Overnight	#	#	6
Private hospital Sameday	0	0	0

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Remoteness (Overnight separations) 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Crohn's disease	Ulcerative colitis	Total
Inner regional	43/373 (12)	43/440 (10)	86/813 (11)
Major Cities	322/373 (86)	384/440 (87)	706/813 (87)
Outer regional	8/373 (2)	13/440 (3)	21/813 (3)
Remote	0	0	0
Very Remote	0	0	0

Age groups (Overnight separations) 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Crohn's disease	Ulcerative colitis	Total
0-9 YEARS	58/373 (16)	86/440 (20)	144/813 (18)
10-14 YEARS	152/373 (41)	182/440 (41)	334/813 (41)
15-17 YEARS	163/373 (44)	172/440 (39)	335/813 (41)

Urgency Status (Overnight separations) 2021 (source: AIHW acute hospital inpatient data Crohn's disease and ulcerative colitis (0-17 years) 2021)

	Crohn's disease	Ulcerative colitis	Total
Elective	124/362 (34)	131/430 (30)	255/792 (32)
Emergency	238/362 (66)	299/430 (70)	537/792 (68)

NB Urgency status isn't assigned or is unknown for some cases not included

Data criteria

- Age less than 18
- Separation date between 1 January 2021 and 31 December 2021 or 1 December 2013 and 30 November 2014.
- Crohn's disease: K50.0, K50.1, K50.8 and K50.9
- Ulcerative Colitis: K51.0, K51.2, K51.3, K51.4, K51.5, K51.8, K51.9 and K52.3
- Data excludes newborns with only unqualified days, boarders and posthumous organ procurement
- Data exclude hospitalisations in WA with a contracted patient status of 'Inter-hospital contracted patient to private sector hospital', to adjust for separations recorded on both sides of contractual care arrangements
- Data sources: National Hospital Morbidity databases for, 2020-21, 2021-22, 2012-13, 2013-14.

Appendix 3 - Organisational survey findings and the Australian IBD Standards

Source for all tables in Appendix 3: CCA Hospital Audit 2021 and 2014

Standard A: High-quality clinical care

A1: The IBD team

	2021 n/N (%)	**2014** n/N (%)
The IBD Service has a named clinical lead who is a paediatric gastroenterologist	7/8 (88)	4/6 (67)

	2021 Total, mean, % w FTE#	**2014** Total, mean, % w FTE#
FTE paediatric gastroenterologists on site	24.7, 3.1 (88)	21, 3.6 (100)
General paediatricians with an interest in gastroenterology on site	2.0, 0.3 (13)	Not asked
Paediatric gastroenterologists w/ a fractional appointment, VMO, or substantive appointment ≥ 0.5 FTE	22.0, 2.8 (75)	15, 2.5 (83)
FTE paediatric gastroenterologists w/ clinical focus on/responsibility for IBD	13.8, 1.7 (88)	14, 2.4 (100)
FTE paediatric colorectal surgeons on site	6.5, 0.8 (50)	5, 0.8 (50)
FTE paediatric IBD nurse specialists on site##	6.0, 0.8 (63)	3, 0.5 (67)
FTE paediatric IBD nurse specialists w/ ongoing secure funded positions	5.2, 0.7 (50)	2, 0.3 (33)
FTE paediatric clinical trial nurses on site	2.0, 0.3 (13)	2, 0.4 (33)
FTE paediatric stoma nurses on site	5.6, 0.7 (63)	6, 1 (100)
FTE paediatric dietitians or dietitians w/ suitable paediatric experience allocated to gastroenterology	4.4, 0.6 (75)	5, 0.8 (100)
FTE administrators attached to the paediatric IBD team	2.0, 0.3 (38)	1, 0.2 (17)

Note. N = 8; #Percentage of sites with full-time equivalent > 0; ##Excludes clinical trial nurses

A2: Essential supporting services

	2021 n/N (%)	**2014** n/N (%)
There is a clear pathway for referring IBD patients to a paediatric rheumatologist	7/8 (88)	4/6 (67)
The IBD Service is supported by a radiologist with a special interest in paediatric gastroenterology	4/8 (50)	4/6 (67)
The IBD Service is supported by a named pharmacist with a special interest in IBD or paediatric gastroenterology	2/8 (25)	4/6 (67)
There is defined access to a named paediatric ophthalmologist	1/8 (13)	3/6 (50)
The IBD Service is supported by a histopathologist with an interest in paediatric gastroenterology	6/8 (75)	6/6 (100)

	2021 n/N (%)	2014 n/N (%)
The IBD Service includes a paediatric mental health clinician	0/8 (0)	1/6 (17)
Paediatric patients with IBD can be referred to appropriate mental health services	6/8 (75)	6/6 (100)
Families and carers of paediatric patients with IBD can be referred to appropriate mental health services	5/8 (63)	6/6 (100)
Information is available for IBD patients who wish to access counselling support, e.g. via GP patient care plans	8/8 (100)	6/6 (100)

A3: Multidisciplinary working

A3.1: IBD team meetings

	2021 n/N (%)	2014 n/N (%)
There is a multidisciplinary meeting in which complex IBD cases can be discussed	6/8 (75)	4/6 (67)
Weekly	2/6 (33)	-
Fortnightly	3/6 (50)	-
Monthly	1/6 (17)	-
Decisions from the multidisciplinary team are documented in the patient notes and fed back to the patient	6/6 (100)	4/4 (100)
Attendance (*Always/Sometimes*) by:		
Paediatric gastroenterology dietitian	3/6 (50)	2/4 (50)
Paediatric pharmacist	3/6 (50)	1/4 (25)
Paediatric mental health clinician	0/6 (100)	NA
Administrator	1/6 (17)	0/4 (0)

Complex surgical procedures are undertaken following joint discussion between medical/surgical and other multidisciplinary team members in a formal IBD Multidisciplinary Team Meeting or joint outpatient clinic.

1	12.5 %
7	87.5 %

A3.2: Medical/surgical interaction

	2021 n/N (%)	2014 n/N (%)
Complex surgical procedures are undertaken following joint discussion between medical/surgical and other multidisciplinary team in meeting or clinic	7/8 (88)	NA

A4: Referral of suspected IBD patients

	2021 n/N (%)	2014 n/N (%)
Suspected IBD patients can be referred to either paediatric gastroenterology, paediatric IBD or paediatric surgical clinics	6/8 (75)	6/6 (100)
There is an agreed referral pathway for urgent paediatric out-patients between GPs and hospitals	7/8 (88)	6/6 (100)

All urgent referrals are seen within 4 weeks or more rapidly if clinically necessary	8/8 (100)	6/6 (100)
Guidance has been developed to help GPs identify and refer symptomatic patients in whom IBD is suspected and when a review of diagnosis of patients with unresponsive, atypical or troublesome abdominal symptoms should occur	5/8 (63)	2/6 (33)

A5: Access to nutritional support and therapy

	2021 n/N (%)	**2014** n/N (%)
IBD patients can be referred to a paediatric dietitian experienced in the dietary management of IBD		
Public service	8/8 (100)	1/6 (17)
Private service	0/8 (100)	5/6 (83)
Exclusive enteral nutrition as a primary treatment is available to patients with Crohn's disease, both as inpatients and outpatients	8/8 (100)	6/6 (100)
Information given to all new IBD patients includes nutritional advice	8/8 (100)	5/6 (83)
Regular assessment (minimum 4 monthly) occurs to ensure that nutritional intake is appropriate to facilitate normal growth and pubertal development	6/8 (75)	4/6 (67)
Home enteral and, where applicable, home parenteral nutrition provision and monitoring is always available to patients either locally or by a regional centre	8/8 (100)	5/6 (83)

A6: Arrangements for the use of immunomodulator and biological therapies

	2021 Median (Q1, Q3)	**2014** Median (Q1, Q3)
Crohn's disease patients (%) on infliximab	45 (31.3, 53.3)	33 (25, 40)
Crohn's disease patients (%) on adalimumab	10 (9.5, 13)	6 (1, 10)
Ulcerative colitis patients (%) on infliximab	25 (18.5, 35)	3 (1, 10)
Ulcerative colitis patients (%) on adalimumab	5 (3.5, 7)	NA
IBD-unspecified patients (%) on infliximab	12 (7.5, 31.3)	NA
IBD-unspecified patients (%) on adalimumab	2.5 (0, 8.5)	NA
All infliximab patients (%) that remain on immunomodulators	77.5 (72.3, 86.3)	NA
All adalimumab patients (%) that remain on immunomodulators	50 (50, 60.3)	NA
How long do your patients remain on immunomodulators?	282.5 (143, 625)	NA
	2021 Median, total	
Estimate how many patients use other, new, off-label IBD medications in the last 12 months.	5, 56	

	2021 n/N (%)	2014 n/N (%)
Policy/protocol for screening for tuberculosis, hepatitis B and other relevant infections.	7/8 (88)	5/6 (83)
Vaccination program for infections (e.g., hepatitis B, Varicella zoster) considered before starting biological therapies.	8/8 (100)	6/6 (100)
Policy for covid vaccination for patients on immunosuppressants	8/8 (100)	NA
All patients and, when relevant, parents are counselled about the risk of malignancy and sepsis prior to starting immunosuppressive therapy.	8/8 (100)	6/6 (100)
Local protocols for the administration of biological therapies	7/8 (88)	6/6 (100)
Process for white blood cell measurement of immunosuppressive treatment patients at least every 3 months.	6/8 (75)	5/6 (83)
Protocols for biologic therapies include pre-treatment, actions for infusion reactions and accelerated infusions	7/8 (88)	6/6 (100)
Policy/protocol to guide response if white cell counts are low or other blood test abnormalities are observed; a named individual acts on abnormal results and communicates with GPs and patients, if appropriate.	5/8 (63)	2/6 (33)
Choice for immunosuppressive therapy patients regarding treatment monitoring in the hospital or community	4/8 (50)	4/6 (67)
Biologic therapy patients reviewed at least 3 monthly (i.e., directly or email/telephone) to monitor efficacy and adverse effects	6/8 (75)	5/6 (83)
Local patient adverse events information sheet given to all patients on immunosuppressive and biological treatments	4/8 (50)	4/6 (67)
Shared-care arrangements between primary and secondary care for monitoring and prescribing of immunosuppressive drugs (i.e., advice for monitoring frequency and abnormal results)	3/8 (38)	3/6 (50)
Combination immunomodulator and biologic therapy patients are subject to regular audit for outcome monitoring	5/8 (63)	NA

A7: Surgery for IBD

	2021 n/N (%)	2014 n/N (%)
Surgeons perform ileo-anal pouch surgery for people age <18 years on site	6/8 (75)	5/6 (83)
Majority of ileo-anal pouch operations undertaken by paediatric surgeon in conjunction with adult colorectal surgeon	6/6 (100)	3/6 (50)
Formal regular governance process to review surgical morbidity and mortality within the hospital/health network, including review or audit of post-operative complications	7/8 (88)	6/6 (100)
Facilities and trained paediatric surgeons to offer laparoscopic /laparoscopically-assisted surgery	8/8 (100)	6/6 (100)
Complex surgical procedures undertaken w/ joint discussion between medical/surgical and other multidisciplinary team members in a formal IBD Multidisciplinary Team Meeting or joint outpatient clinic.	7/8 (88)	5/6 (83)

Patients considered for pouch surgery referred to pathological assessment in case of diagnostic uncertainty.	7/8 (88)	6/6 (100)
Anaesthesia for IBD surgery carried out by accredited paediatric anaesthetists	8/8 (100)	-
One consultant surgeon with dedicated Paediatric IBD experience is the nominated lead for IBD surgery within the hospital/network. They support decision-making and/or surgery for complex IBD cases	4/8 (50)	3/6 (50)
Pouch failure (and salvage) is managed in, or routinely referred to an agreed regional specialist unit, with appropriate expertise in re-operative pouch surgery	4/8 (50)	5/6 (83)
There is annual review of IBD surgical service with review of activity, mortality and morbidity.	0/8 (0)	0/6 (0)

Crohn's disease procedure procedures Common procedures for multiday episodes (age <18) from January 1 to 31 December 2021	**2021** n	**2014** n
Restorative proctectomy	0	NA
Total proctocolectomy with ileo-anal anastomosis (including formation of temporary ileostomy)	0	0
Rectosigmoidectomy with formation of stoma Hartmann's procedure	0	0
Abdominoperineal proctectomy (APR)	0	0
High anterior resection of rectum	0	0
Low anterior resection of rectum	0	0
Ultra low anterior resection of rectum	0	0
Perineal proctectomy	0	0
Left hemicolectomy with anastomosis (incl. formation of stoma) Limited excision of large intestine with anastomosis	0	1
Limited excision of large intestine with formation of stoma	0	NA
Right hemicolectomy with anastomosis	5	1
Right hemicolectomy with formation of stoma	0	1
Subtotal colectomy with anastomosis	0	0
Subtotal colectomy with formation of stoma	0	0
Total colectomy with ileostomy	0	0
Total colectomy with ileorectal anastomosis	0	0
Strictureplasty of small intestine	0	1
Resection of small intestine with formation of stoma	0	1
Resection of small intestine with anastomosis	0	0
Anorectal examination	4	NA
Insertion adjustment or removal of anal seton	5	NA
Closure of colostomy, loop ileostomy or other stoma	0	NA
Total:	14	5

Ulcerative colitis procedures Common procedures for multiday episodes (age <18) from January 1 to 31 December 2021	**2021** n	**2014** n
Restorative proctectomy	2	6

Total proctocolectomy with ileo-anal anastomosis (including formation of temporary ileostomy)	1	0
Rectosigmoidectomy with formation of stoma - Hartmann's Procedure	0	1
Abdominoperineal proctectomy (APR)	0	0
High anterior resection of rectum	0	0
Low anterior resection of rectum	0	0
Ultra low anterior resection of rectum	0	0
Perineal proctectomy	0	0
Left hemicolectomy with anastomosis (incl. formation of stoma)	0	0
Limited excision of large intestine with anastomosis	0	0
Limited excision of large intestine with formation of stoma	0	0
Right hemicolectomy with anastomosis	0	0
Right hemicolectomy with formation of stoma	0	0
Subtotal colectomy with anastomosis	0	0
Subtotal colectomy with formation of stoma	3	0
Total colectomy with ileostomy	0	2
Total colectomy with ileorectal anastomosis	0	1
Strictureplasty of small intestine	0	NA
Resection of small intestine with formation of stoma	0	0
Resection of small intestine with anastomosis	0	0
Anorectal examination	2	NA
Insertion adjustment or removal of anal seton	1	NA
Closure of colostomy, loop ileostomy or other stoma	1	NA
Total:	10	10

A8: Inpatient facilities

	2021 n/N (%)	**2014** n/N (%)
There is an identifiable paediatric gastroenterology ward	4/8 (50)	2/6 (33)
IBD or suspected IBD patients are usually triaged to the gastroenterology ward on admission	4/4 (100)	2/2 (100)
There is a paediatric intensive care unit (ICU) and a mixed medical/surgical high dependency unit (HDU).	6/8 (75)	5/6 (83)
On the main ward that gastroenterology patients are managed, there is at least one toilet per 3 beds.	7/8 (88)	4/6 (67)
The toilets have floor to ceiling partitions, full height doors and good ventilation	8/8 (100)	6/6 (100)
Gastroenterology and colorectal surgical facilities are on the same site	8/8 (100)	6/6 (100)

A9: Access to diagnostic services

	N	Mean, SD	Min	Max	2014 mean
How long does it take for a patient referred with suspected IBD to have their diagnosis confirmed? (days)	8	30.9 (7.8)	21	42	-
How long does it take for a patient referred with suspected IBD to be seen in clinic for the first time? (days)	8	17.1 (7.3)	7	30	-

	2021 n/N (%)	2014 n/N (%)
There is a gastrointestinal pathologist assessment available before surgery, which may involve referral of cases to a nationally recognised expert in the diagnosis and differential diagnosis, of chronic inflammatory bowel disease		
Yes	4/8 (50)	6/6 (100)
No	1/8 (13)	0/6 (0)
Uncertain	3/8 (38)	0/6 (0)
For inpatients there is access to on-site ultrasound within 24 hours where required	8/8 (100)	6/6 (100)
For inpatients there is access to on-site CT within 24 hours where required in a child friendly and suitably equipped environment	8/8 (100)	6/6 (100)
For inpatients there is access to on-site MRI within 24 hours where required a child friendly and suitably equipped environment	8/8 (100)	4/6 (67)
It is routine practice for patients with acute severe ulcerative colitis to have a plain abdominal x-ray on admission	8/8 (100)	4/6 (67)
X-ray reports of presence of toxic megacolon (transverse>4cm in children under 10 years and >6cm in children over 10 years) are documented in the notes or on radiology report. Documentation is by the most senior member of the team who comments on initial X-ray	6/8 (75)	4/6 (67)
Paediatric patients undergo endoscopy in an age-appropriate environment, carried out by someone with training or extensive experience in paediatric endoscopy and appropriate training recognized by the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy (CCRTGE)	7/8 (88)	6/6 (100)
There is a process for urgent access to endoscopy, so that patients admitted with relapse can be scoped within 72 hours of admission	8/8 (100)	6/6 (100)
All histological reports are available within 5 working days	6/8 (75)	5/6 (83)
Urgent histology biopsies can be reported within 2 days	7/8 (88)	6/6 (100)
When required, drainage of an abscess can be carried out by interventional radiology	7/8 (88)	4/6 (67)
There is outpatient access to ultrasound/CT/MRI studies and endoscopic assessment within 4 weeks	6/8 (75)	3/6 (50)
Small bowel MRI is available as an alternative to CT scans	8/8 (100)	6/6 (100)
There is a consultant radiologist who primarily reports all paediatric gastrointestinal radiology in the hospital	6/8 (75)	5/6 (83)
PUCAI (paediatric UC disease activity index score) is used at day 3 and 5 for assessment of patients with acute severe ulcerative colitis	7/8 (88)	6/6 (100)

A10: Inpatient care

	2021 n/N (%)	2014 n/N (%)
Policy / protocol that IBD patients have a weight and nutritional risk assessment, such as the PSGNA/PNST, STAMP, STRONGkids or PYMS score, on admission to hospital	5/8 (63)	1/6 (17)

Policy / protocol that IBD patients who have diarrhoea, have a stool sample sent for standard stool culture and Clostridium difficile toxin on admission	5/8 (63)	4/6 (67)
Policy / protocol that IBD patients have a stool chart recorded during hospitalisation	5/8 (63)	4/6 (67)
Policy / protocol for suspected new IBD presentation	5/8 (63)	4/6 (67)
Policy / protocol for flare of ulcerative colitis	3/8 (38)	3/6 (50)
Policy / protocol for flare of Crohn's disease	3/8 (38)	2/6 (33)
Policy / protocol for acute severe ulcerative colitis	4/8 (50)	3/6 (50)
There is an acute pain management team available on site	8/8 (100)	6/6 (100)
Pain scores are routinely included in nursing observations for IBD patients	8/8 (100)	3/6 (50)
Inpatients have access to an IBD nurse during their admission	5/8 (63)	5/6 (83)
It is usual practice to refer an inpatient with severe pain (measured by pain scores) to the acute pain management team	8/8 (100)	6/6 (100)
There is access to a stoma nurse during hospitalization	7/8 (88)	6/6 (100)
A named pharmacist with special interest in IBD is available to carry out inpatient drug reviews	2/8 (25)	3/6 (50)

A11: Outpatient care

	2021 n/N (%)	2014 n/N (%)
Does your hospital have a paediatric specific Gastroenterology Clinic?	8/8 (100)	6/6 (100)
Does your hospital have a paediatric specific IBD Clinic?	5/8 (63)	4/6 (67)
All of the following are usually documented for all patients at clinic review: number of liquid stools per day, abdominal pain, weight loss, general well-being, psychological concerns, pubertal growth (Tanner staging) where required and height and weight recorded on appropriate percentile charts.	7/8 (88)	5/6 (83)
Systems are in place to ensure that all patients currently under hospital review are identified and offered surveillance colonoscopy in accordance with guidelines.	6/8 (75)	2/6 (33)
Steroid usage is recorded to ensure that patients who have had 3 months or continuous steroid use are identified	6/8 (75)	2/6 (33)
All children with ulcerative colitis who have had the disease for more than 8 years are formally identified and a surveillance plan made and shared with adult services	4/8 (50)	2/6 (33)
Bone densitometry is offered routinely to all patients who have received more than 3 months of corticosteroids.	3/8 (38)	2/6 (33)
Annual data is collected and presented on: the percentage of patients who remain on steroids continuously for 3 months, the percentage of these patients discussed at MDT and the percentage started on additional therapy (e.g. immunosuppressives, anti-TNF or surgery).	0/8 (0)	2/6 (33)

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

	2021 n/N (%)	2014 n/N (%)
There is a transitional care service within the hospital to support young people being transferred from a paediatric service. A coordinator is	6/8 (75)	5/6 (83)

responsible for the preparation and oversight of such transitional care(e.g. IBD nurse specialist)		
Each young person with IBD has an individual transition plan	4/8 (50)	3/6 (50)
Age-appropriate written and verbal advice is provided to patient and/or carer on day-to-day management of symptoms and treatment	5/8 (63)	6/6 (100)
Support and education is provided on lifestyle issues (e.g. sexual health, smoking, alcohol, recreational drug use) in young people with IBD	6/8 (75)	6/6 (100)
The IBD service has a specific paediatric-to-adult transition policy	4/8 (50)	3/6 (50)
The IBD service has a joint transition clinic with adult services6p	6/8 (75)	2/6 (33)

Standard B: Local delivery of care

B1: Arrangements for shared care

	2021 n/N (%)	2014 n/N (%)
When a patient is discharged back to primary care, the GP is routinely given clear instruction about the need and criteria for annual review, including assessment of the need for:		
Colorectal cancer surveillance	0/8 (0)	2/6 (33)
Renal function	1/8 (13)	2/6 (33)
Bone densitometry	1/8 (13)	1/6 (17)
None	7/8 (88)	4/6 (67)

Standard C: Maintaining a patient-centred service

C1: Information on the IBD service

	2021 n/N (%)	2014 n/N (%)
Patients and carers are provided with written information regarding how to access IBD services and arrangements for follow up.	8/8 (100)	5/6 (83)
There is clear guidance as to how patients and carers can seek a second opinion if they wish.	5/8 (63)	3/6 (50)

C2: Rapid access to specialist advice

	2021 n/N (%)	2014 n/N (%)
There is written information for patients and carers with IBD on whom to contact in the event of a relapse	7/8 (88)	5/6 (83)
Patients and carers have access to contact an IBD specialist nurse or doctor by telephone	5/8 (63)	6/6 (100)
Patients and carers are able to contact an IBD specialist nurse or doctor via an email service	7/8 (88)	6/6 (100)
Patients who contact the service via telephone or email are answered within 48 hours by an IBD specialist nurse or doctor	6/8 (75)	6/6 (100)
Specialist review (face-to-face) for relapsed patients is available		
Within 7 working days	6/8 (75)	6/6 (100)

8 to 14 working days	2/8 (25)	0/6 (0)
Patients who contact the service via telephone or email are answered within 48 hours by an IBD specialist nurse or doctor	6/8 (75)	0/6 (0)

C3: Supporting patients to exercise choice between treatments &
C4: Supporting patients to exercise choice between different follow-up care models

	2021 n/N (%)	2014 n/N (%)
Patients and carers are actively involved in management decisions about care, with a clear structured pathway for the patient to discuss his or her treatment with the gastroenterology, surgical, dietetics and other members of the multidisciplinary team	8/8 (100)	6/6 (100)
Patients are offered a choice of annual review including:		
Hospital clinic	6/8 (75)	6/6 (100)
Telephone clinic	3/8 (38)	1/6 (17)
Review in primary care	1/8 (13)	0/6 (0)
None	2/8 (25)	0/6 (0)

C5: Involvement of patients in service improvement

	2021 n/N (%)	2014 n/N (%)
IBD patients are given the opportunity to provide feedback on their care	7/8 (88)	4/6 (67)
At least one of the following means of assessing patient satisfaction is used: - An annual survey of a significant number of patients IBD service subscribes to patient opinion or similar feedback service. - Comment cards given to randomly sampled outpatients and inpatients	0/8 (0)	0/6 (0)
Patients and carers are involved in service planning and improvement	3/8 (38)	1/6 (17)
The service has an IBD patient panel or similar patient involvement group through which patients and carers discuss how the service might be improved with health professionals	0/8 (0)	1/6 (17)
There has been reporting, followed by action planning and change implemented that was carried out as a result of the patient feedback of their care within the last year	1/8 (13)	1/6 (17)

Standard D: Patient education and support

D1: Provision of Information

	2021 n/N (%)	2014 n/N (%)
Age-appropriate written information about IBD in pregnancy and its effects on fertility is available for patients	5/8 (63)	3/6 (50)
Patients are given age-appropriate advice, when required, on issues regarding sexuality and body image. Teams can refer for specialist support locally as appropriate	6/8 (75)	6/6 (100)
There is an agreed clinical pathway between adolescent gynaecology services and IBD Services for shared care	4/8 (50)	1/6 (17)

All newly diagnosed patients and carers are given educational material routinely.	8/8 (100)	6/6 (100)
Written and/or website recommendations about IBD and a range of treatments is available to all patients and carers	8/8 (100)	6/6 (100)
Written and/or website recommendations about IBD and the range of treatments is provided to patients and carers as part of the consultation to support the patient's decisions.	8/8 (100)	6/6 (100)
There is access to a translator for all face-to-face and telephone contacts between patients and carers and the IBD specialist. Only answer 'yes' if a translator is available for ALL face-to-face and telephone contact.	8/8 (100)	5/6 (83)
Information is available that is appropriate to the age, understanding and communication needs of paediatric patients	5/8 (63)	6/6 (100)
A selection of written information is available for patients and carers in languages other than English	6/8 (75)	1/6 (17)
Stable patients who are referred back to primary care are given a clear plan about what to do in the event of a flare up	7/8 (88)	3/6 (50)

D2: Education for patients

	2021 n/N (%)	2014 n/N (%)
All newly diagnosed patients and carers are offered a 'patient education' session routinely	6/8 (75)	4/6 (67)
Your hospital routinely offers regular education opportunities for all IBD patients and their families, either as individuals or in groups.	4/8 (50)	4/6 (67)

D3: Patient-support groups

	2021 n/N (%)	2014 n/N (%)
Written information is made available to all new patients and carers, providing details of relevant patient organisations	7/8 (87.5)	6/6 (100)
All IBD patients and carers are provided with information about their local patient support groups	5/8 (62.5)	5/6 (83)

Standard E: Data, information technology and audit

E1: Register of patients under the care of the IBD service &
E2: Using IBD electronic clinical management system

	2021 n/N (%)	2014 n/N (%)
The IBD service has a searchable database or registry of paediatric IBD patients	6/8 (75)	5/6 (83)
The database is updated with clinical data about paediatric IBD patients receiving hospital care	3/6 (50)	2/5 (40)
The database is updated with patients on biological therapy	5/6 (83)	3/5 (60)
The database is updated with patients on all immunosuppressives (including biological therapies)	2/6 (33)	0/5 (0)
The database is updated with clinical data about all patients with a diagnosis of IBD	4/6 (67)	2/5 (40)

E3: Participation in audit

	2021 n/N (%)	2014 n/N (%)
IBD patients on both immunomodulator and biological therapy are subject to regular audit for outcome monitoring	5/8 (63)	-
All IBD inpatient deaths are reviewed by the IBD team, an action plan is formulated, and action plan implementation is reviewed at least annually	3/3 (100)	-
There are mortality and morbidity meetings that are attended by a multidisciplinary team, to discuss any deaths and outcomes of surgery. These are minuted and have attendance registers.	7/8 (88)	-

Standard F: Evidence-based practice and research

F1: Training and education

	2021 n/N (%)	2014 n/N (%)
There are education opportunities focussed on IBD for all medical and nursing staff	7/8 (88)	? NA
The IBD team provides IBD training for GPs on an ad hoc basis	1/8 (13)	? NA

F2: Research

	2021 n/N (%)	2014 n/N (%)
The IBD service provides access to age-appropriate clinical trials	5/8 (63)	4/6 (67)
	Total enrolled, mean (SD)	**Total enrolled, mean (SD)**
How many patients were entered into a clinical trial for UC/CD in the last year?	4, 0.8 (0.84)	2 (0, 17)
	n/N (%)	n/N (%)
Do you collaborate on clinical trials with other sites?	6/8 (75)	5/6 (83)
All members of service are encouraged to participate in research, which is supported by the service with monetary support and/or flexible working arrangements	5/8 (63)	2/6 (33)
If 'yes' is this externally funded?	1/5 (20)	2/2 (100)

F3: Service development

	2021 n/N (%)	2014 n/N (%)
An annual review of the IBD Service is carried out	1/8 (13)	-
The annual review is attended by a multidisciplinary team of relevant professionals and there is a reflection on the Service	1/1 (100)	-
An annual action plan is completed as a result of the review and achievement of the actions is reviewed as part of the organisational Quality Plan.	1/1 (100)	-

Appendix 4 - Clinical Audit data tables

Source for all tables in Appendix 4: CCA Hospital Audit 2021 and 2014

Crohn's disease

Demographics

	2021	2014
Crohn's disease cases (total/site)	N = 87	N = 75
	Mean (SD)	Mean (SD)
	12.1 (3.5)	14.1 (2.7)
Age on admission (years)	n/N (%)	n/N (%)
0-1	0/87 (0)	0/75 (0)
2-5	4/87 (5)	0/75 (0)
6-11	27/87 (31)	13/75 (17)
12-17	56/87 (64)**	62/75 (83)
Gender		
Male	43/87 (49)	42/75 (56)
Female	43/87 (49)	33/75 (44)
Other	1/87 (1)	0/75 (0)
Primary reason for admission		
New diagnosis	26/87 (30)	22/75 (29)
Emergency admission	36/87 (41)	34/75 (45)
Planned admission (known case)	10/87 (11)	5/75 (7)
Elective admission for surgery	5/87 (6)	7/75 (9)
Transfer from another site	3/87 (3)	3/75 (4)
Other	7/87 (8)	4/75 (5)
Source of admission		
ED admission	46/87 (53)	45/75 (60)
Referred by GP	7/87 (8)	3/75 (4)
Advised to attend via IBD nurse helpline	2/87 (2)	2/75 (3)
Referred in from Hospital OPD	22/87 (25)	11/75 (15)
Referred in from GE specialist rooms	5/87 (6)	3/75 (4)
Referred in from surgical specialist rooms	2/87 (2)	4/75 (5)
Transfer from another site	5/87 (6)	8/75 (11)
Other	10/87 (11)	6/75 (8)

Has the patient had previous overnight admissions with CD in the two years prior to this admission at this hospital?	40/87 (46)	34/75 (45)
	Median (Q1, Q3)	Median (Q1,Q3)
	1 (1, 2)	2 (1, 3)
	n/N (%)	n/N (%)
Has there been a CD-related admission within the last 30 days?	13/40 (33)	12/34 (35)
The patient was:		
Discharged home	86/87 (99)	72/75 (96)
Transferred to another centre for medical management	1/87 (1)	2/75 (3)
Discharged at own risk	0/0 (0)	0/75 (0)
Discharged to a nursing home or rehabilitation centre	0/0 (0)	0/75 (0)
Transferred to another centre for surgery	0/0 (0)	1/75 (1)
Deceased	0/0 (0)	0/75 (0)
Length of stay (days)	Mean (SD)	Mean (SD)
	11.3# (37.0)	6.7 (6.1)
	n/N (%)	n/N (%)
1-2	26/87 (30)	9/75 (12)
3-6	34/87 (39)	38/75 (51)
7-13	19/87 (22)	20/75 (27)
14-27	5/87 (6)	6/75 (8)
28+	3/87 (3)	2/75 (3)

(n = 2) extreme outliers: 278, 213 days.
**p<0.01

Initial assessment during the first full day following admission

	2021 n/N (%)	2014 n/N (%)
Was duration of disease stated in admission notes? #	48/59 (81)	33/53 (62)
Duration of disease (years) #		
<1	25/37 (68)	5/33 (15)
1 - <2	3/37 (8)	8/33 (24)
2 - <5	7/37 (19)	11/33 (33)
5 - <10	1/37 (3)**	8/33 (24)
≥10	1/37 (3)	1/33 (3)
Was the extent of Crohn's disease at the most recent assessment recorded in the admission notes? #	41/59 (70)	25/53 (47)
Distal 1/3 ileum ± limited cecal disease (L1)	7/41 (17)	
Colonic (L2)	11/41 (27)	
Ileo-colonic (L3)	21/41 (51)	
Upper disease proximal to Ligament of Treitz (L4a)	9/41 (22)	
Upper disease distal to Ligament of Treitz proximal to distal 1/3 ileum (L4b)	5/41 (12)	
Unknown	2/41 (5)	

Was the number of liquid stools per day recorded in the clinical record? ##	53/79 (67)	51/73 (70)
Was the presence of blood in the stools recorded in the clinical record? ###	65/86 (76)	38/73 (52)
Was general wellbeing recorded in the clinical record? ##	66/87 (76)	64/75 (85)
Perineal examination	31/84 (37)	26/74 (35)
Notes recorded the current presence of:		
Fevers	21/87 (24)**	34/75 (45)
Active perineal disease	20/87 (23)	13/75 (17)
Abdominal mass	3/87 (3)	6/75 (8)
Abdominal pain	65/87 (75)	63/75 (84)
Mouth ulcers	11/87 (13)	13/75 (17)
Oro-facial granulomatosis	4/87 (5)	1/75 (1)
Arthralgia	9/87 (10)	7/75 (9)
Arthritis	2/87 (2)	1/75 (1)
Ankylosing spondylitis	0/87 (0)	0/75 (0)
Erythema nodosum	6/87 (7)	1/75 (1)
Pyoderma gangrenosum	0/87 (0)	0/75 (0)
Iritis	3/87 (3)	0/75 (0)
Anal fissure	7/87 (8)	7/75 (9)
Fistula	7/87 (8)	6/75 (8)
Abscess	7/87 (8)	10/75 (13)
Malnutrition	32/87 (37)	26/75 (35)
Was a paediatric Crohn's disease activity index (PCDAI) score recorded?	17/87 (20)	4/69 (6)

Excludes new diagnoses ## Excludes 'N/A' / stoma. ### Excludes 'N/A'.
**p<0.01

Comorbidity

	2021 n/N (%)	2014 n/N (%)
Were any significant comorbid diseases/conditions documented? (select all that apply)		
Yes	23/86 (27)	27/75 (36)
Statement that there were no relevant comorbidities	13/86 (15)	16/75 (21)
None recorded	50/86 (58)	32/75 (43)
Comorbidities:		
Cardiovascular	0/23 (0)	4/27 (15)
Respiratory	7/23 (30)	7/27 (26)
Renal	0/23 (0)	0/27 (0)
Diabetes	0/23 (0)	1/27 (4)
Liver disease	2/23 (9)	0/27 (0)
Active cancer	2/23 (9)	0/27 (0)
Growth failure	1/23 (4)	4/27 (15)
Iron deficiency anaemia	2/23 (9)	1/27 (4)
Psychological condition	7/23 (30)	12/27 (44)

Other	14/23 (61)	9/27 (33)

Medication on admission

	2021 n/N (%)	2014 n/N (%)
Was the patient taking treatment for Crohn's disease on admission?		
Yes	56/87 (64)	49/75 (65)
No	30/87 (35)	25/75 (33)
Not stated	1/87 (1)	1/75 (1)
Treatment(s):		
Sulfasalazine	5/56 (9)	2/49 (4)
Oral 5-ASA	1/56 (2)*	7/49 (14)
Topical 5-ASA	1/56 (2)	0/49 (0)
Oral corticosteroids	11/56 (20)	9/49 (18)
Topical corticosteroids	2/56 (4)	0/49 (0)
Mercaptopurine	7/56 (13)	4/49 (8)
Azathioprine	16/56 (29)**	29/49 (59)
Methotrexate	8/56 (14)	7/49 (14)
Antibiotics	4/56 (7)	4/49 (8)
Exclusive Enteral Nutrition	13/56 (23)	7/49 (14)
Other Dietary therapy	1/56 (2)	0/49 (0)
Allopurinol	0/56 (0)	1/49 (2)
Anti-TNF agent	20/56 (36)	20/49 (41)
Other	12/56 (21)	5/49 (10)
Was there an estimate of compliance recorded?	11/56 (20)	5/49 (10)

*p<0.05, **p<0.01

Smoking status

	2021 n/N (%)	2014 n/N (%)
What was the smoking status of the patient?		
Not documented	84/87 (97)	63/75 (84)
Not currently smoking	3/87 (3)*	11/75 (15)
Current	0/87 (0)	1/75 (1)

*p<0.05,

Other assessment during admission

Prolonged steroid use

	2021 n/N (%)	2014 n/N (%)
In the 12 months prior to admission was the patient taking oral steroids for CD (at any time) for >3 months?	1/87 (1)*	8/75 (11)
Was an appropriate dose reduction planned?	1/1 (100)	5/8 (63)
Was bone protection used?	0/1 (0)	1/8 (13)
Had a DEXA scan been done within 5 years?	0/1 (0)	0/8 (0)

What steroid-sparing strategies were tried?		
Thiopurine	1/1 (100)	8/8 (100)
Methotrexate	0/1 (0)	2/8 (25)
Anti-TNF agent	1/1 (100)	4/8 (50)
None	0/1 (0)	0/8 (0)
Other	0/1 (0)	0/8 (0)

**p<0.01

Weight assessment and dietetic support during admission

	2021 n/N (%)	2014 n/N (%)
Was a dietetic assessment recorded?	55/86 (64)	46/75 (61)
Was a formal nutritional risk assessment documented in the patient record?	17/87 (20)	14/75 (19)
By whom?		
Dietitian	17/17 (100)	11/14 (79)
Nurse	0/17 (0)	2/14 (14)
Unclear	0/17 (0)	1/14 (7)
Was the patient's weight recorded within two days of admission?	83/87 (95)	64/75 (85)
Was the patient's height recorded?	44/87 (51)	33/69 (48)
Was the patient's weight recorded within two days of discharge?	54/86 (63)	33/75 (44)
Was BMI recorded?	38/86 (44)	28/75 (37)
Was it documented that a dietitian saw the patient?		
Yes	53/87 (61)	46/75 (61)
No	24/87 (28)	26/75 (35)
Not applicable	10/87 (11)	3/75 (4)
Was dietary treatment recommended?		
Yes	52/87 (60)	47/75 (63)
No	26/87 (30)	18/75 (24)
NR	9/87 (10)	10/75 (13)

Investigations

	2021 n/N (%)	2014 n/N (%)
Results recorded within 24 hours of admission:		
CRP (mg/L)	72/87 (83)	62/75 (83)
Hb (g/dL)	76/87 (87)	69/75 (92)
Albumin (g/L)	73/87 (84)	62/75 (83)
Faecal calprotectin (µg/g)	32/87 (37)	11/75 (15)
Haematocrit ()	76/87 (87)	63/75 (84)
Esr (mm/hr)	48/87 (55)	27/75 (36)
Stool sample sent for stool culture/PCR within 48 hours of admission#	41/77 (53)	33/66 (50)
Stool culture/PCR positive	5/41 (12)	2/33 (6)

Stool sample sent for *Clostridium difficile* toxin within 48 hours of admission#	34/77 (44)	25/66 (38)
C. diff positive	3/34 (9)	0/25 (0)
Imaging used during the admission		
No imaging performed	27/87 (31)	17/75 (23)
Abdominal X-ray	24/87 (28)	19/75 (25)
Abdominal ultrasound (not small bowel specific)	26/87 (30)	26/75 (35)
Specific small bowel ultrasound	5/87 (6)	3/75 (4)
Abdominal CT scan	5/87 (6)	10/75 (13)
MR Enterography	15/87 (17)	11/75 (15)
Other	16/87 (18)	18/75 (24)

Care team and ward

	2021 n/N (%)	2014 n/N (%)
Which specialty was responsible for the patient's care 24 hours after admission?		
Gastroenterology	4/87 (5)	-
Paediatric acute or general medicine	15/87 (17)	-
Paediatric colorectal surgery	1/87 (1)	-
Paediatric gastroenterology	61/87 (70)	-
Paediatric general surgery	6/87 (7)	-
Was a paediatric gastroenterology consultant or paediatric registrar/fellow consulted?		
Yes	77/87 (89)	71/74 (96)
No	5/87 (6)	3/74 (4)
Not required	5/87 (6)	0/74 (0)
Paediatric surgeon, paediatric colorectal surgeon, colorectal surgeon or respective registrars consulted		
Yes	28/85 (33)	27/73 (37)
No	27/85 (32)	32/73 (44)
Not required	30/85 (35)	14/73 (19)
IBD nurse specialist saw the patient during admission		
Yes	20/87 (23)	25/75 (33)
No	67/87 (77)	-
Patient cared for on a specialist gastroenterology ward	57/87 (66)	17/75 (23)
Paediatric gastroenterology	45/57 (79)	-
Joint paediatric gastroenterology/surgical	6/57 (11)	-
Paediatric medical	6/57 (11)	-
Patient received short term psychological support Total [%] & w. psychological comorbidity [%]	30/87 (35) 2/5 (40)	20/75 (27) -
Psychologist	6/30 (20)*	10/20 (50)
Psychiatrist	1/30 (3)*	5/20 (25)
Social worker	15/30 (50)	11/20 (55)
Pastoral care	2/30 (7)	0/20 (0)

Other	11/30 (37)	1/20 (5)
Patient received short-term psychotropic medication #	7/77 (9)	4/73 (5)
Patient discussed at a multidisciplinary team meeting ##	26/81 (32)	12/68 (18)

Excludes 'N/A' ## Excludes elective admissions
*p<0.05

Medical intervention
Use of antithrombotic therapy

	2021 n/N (%)	2014 n/N (%)
Was the patient given DVT/PE prophylaxis? Yes	7/87 (8)*	14/75 (19)
Did the patient have a thrombotic episode during this admission? Yes No	0/82 (0)	0/68 (0)

*p<0.05

Steroid and other therapy

	2021 n/N (%)	2014 n/N (%)
Were corticosteroids initiated during this admission?	25/80 (31)	24/68 (35)
IV	17/26 (65)	19/24 (79)
Oral	15/26 (58)	13/24 (54)
Topical	0/26 (0)	0/24 (0)
Other therapies started during the admission (if non-elective patient)		
None	23/80 (29)	29/68 (43)
5-Aminosalicylates	3/80 (4)	3/68 (4)
Thiopurine therapy	8/80 (10)	10/68 (15)
Methotrexate	4/80 (5)	2/68 (3)
Anti-TNF	9/80 (11)	6/68 (9)
Other nutrition support (e.g. EEN, supplemental nutrition, CDED , SCD, PEN)	29/80 (36)	19/68 (28)
Other	23/80 (29)	16/68 (24)

Surgical intervention

	2021 n/N (%)	2014 n/N (%)
Did the patient have surgery on this admission? (Yes)	12/87 (14)	12/75 (16)
Was there a delay of more than 48 hours between decision to operate and surgery? (Yes, excludes unclear)	0/8 (0)	0/5 (0)
Was the ASA status recorded on an anaesthetic chart?	10/12 (83)	9/12 (75)
What was the status?		
1	2/10 (20)	1/9 (11)
2	4/10 (40)	6/9 (67)
3	4/10 (40)	2/9 (22)
4	0/10 (0)	0/9 (0)
Indications for surgery		
Obstruction	2/12 (17)	2/12 (17)

Perforation	2/12 (17)	0/12 (0)
Abscess	4/12 (33)	6/12 (50)
Formation of ileostomy	0/12 (0)	1/12 (8)
Closure of stoma	0/12 (0)	2/12 (17)
Failure of medical therapy	2/12 (17)	2/12 (17)
Bleeding	0/12 (0)	1/12 (8)
Completion proctectomy	0/12 (0)	0/12 (0)
Dysplasia	0/12 (0)	0/12 (0)
Cancer	1/12 (8)	0/12 (0)
Fistula	3/12 (25)	0/12 (0)
Other indication	3/12 (25)	2/12 (17)
Intervention type		
Ileocolonic resection	2/12 (17)	1/12 (8)
Ileal/jejunal resection	0/12 (0)	1/12 (8)
Stricturoplasty	0/12 (0)	0/12 (0)
Segmental/extended colectomy	1/12 (8)	0/12 (0)
Subtotal colectomy	0/12 (0)	1/12 (8)
Proctocolectomy	0/12 (0)	0/12 (0)
Resection of Intra-abdominal fistula	0/12 (0)	0/12 (0)
Completion proctectomy	0/12 (0)	0/12 (0)
Drainage of abscess	3/12 (25)	6/12 (50)
Formation of ileostomy or colostomy	0/12 (0)	1/12 (8)
Revision of stoma	0/12 (0)	0/12 (0)
Closure of stoma	0/12 (0)	2/12 (17)
Perineal procedure	2/12 (17)	1/12 (8)
Division of adhesions	0/12 (0)	0/12 (0)
Seton Insertion	2/12 (17)	3/12 (25)
Other intervention	6/12 (50)	3/12 (25)
Was the surgery done laparoscopically or laparoscopically assisted?		
Yes	4/12 (33)	3/12 (25)
No	7/12 (58)	9/12 (75)
Unclear	1/12 (8)	0/12 (0)
Was the patient seen by a stomal nurse prior to surgery? #	1/5 (20)	3/5 (60)
Was the patient seen by a stomal therapy nurse during this admission? #	1/5 (20)	3/5 (60)
Postoperative complications	2/12 (17)	3/12 (25)
Wound infection	0/12 (0)	1/12 (8)
Rectal stump complications	0/12 (0)	0/12 (0)
Intra-abdominal bleeding	0/12 (0)	0/12 (0)
Intra-abdominal abscess	0/12 (0)	0/12 (0)
Anastomotic leakage	0/12 (0)	0/12 (0)
Stoma complications	0/12 (0)	0/12 (0)
Deep vein thrombosis (DVT)	0/12 (0)	0/12 (0)
Pulmonary embolus (PE)	0/12 (0)	0/12 (0)

Small bowel obstruction	0/12 (0)	0/12 (0)
Ileus	0/12 (0)	1/12 (8)
Total parenteral nutrition (TPN)	2/12 (17)	2/12 (17)
Cardiac	0/12 (0)	0/12 (0)
Respiratory	0/12 (0)	0/12 (0)
Clostridium difficile-associated diarrhoea (CDAD)	0/12 (0)	1/12 (8)
Malnutrition	0/12 (0)	0/12 (0)
Reoperation (for any reason)	1/12 (8)	1/12 (8)
Other	1/12 (8)	1/12 (8)
Was the patient newly prescribed any of the following drugs on discharge, i.e. additional to those on presentation? (select all that apply)	6/12 (50)	6/12 (50)
Azathioprine	0/6 (0)	1/12 (8)
Mercaptopurine	0/6 (0)	0/12 (0)
Metronidazole	4/6 (67)	1/12 (8)
5-ASA	0/6 (0)	1/12 (8)
Methotrexate	1/6 (17)	0/12 (0)
Infliximab	1/6 (17)	2/12 (17)
Adalimumab	0/6 (0)	0/12 (0)
Other	3/6 (50)	3/12 (25)

Excludes strictureplasty, abscess drainage, perineal procedure, adhesion division, seton insertion, other

Anaemia

	2021 n/N (%)	2014 n/N (%)
Was the patient anaemic on admission?		
Yes	40/87 (46)	36/75 (48)
No	41/87 (47)	33/75 (44)
Not recorded	6/87 (7)	6/75 (8)
Was the anaemia noted or commented on by the treating team?		
Yes	27/40 (68)	26/36 (72)
No	7/40 (18)	5/36 (14)
Not recorded	6/40 (15)	5/36 (14)
Was anaemia (at presentation or during hospitalization) due to iron deficiency?		
Yes	27/40 (68)	19/36 (53)
No	0/40 (0)*	4/36 (11)
Other cause/uncertain	0/0	2/36 (6)
Not recorded	13/40 (33)	11/36 (31)
What treatment was administered for anaemia?		
Oral iron	4/27 (15)	4/19 (21)
IV iron	20/27 (74)	13/19 (68)
Blood transfusion	0/27 (0)	1/19 (5)
Nutritional advice	5/27 (19)	1/19 (5)
Not recorded	0/27 (0)	1/19 (5)

***p<0.05**

Discharge arrangements

	2021 n/N (%)	2014 n/N (%)
Was the patient taking oral steroids on discharge?		
Yes	27/86 (31)	25/72 (35)
No	59/86 (69)	46/72 (64)
Not applicable	0/86 (0)	1/72 (1)
Was a steroid reduction program stated on discharge?		
Yes	21/27 (78)	21/25 (84)
No	5/27 (19)	4/25 (16)
Not applicable	1/27 (4)	0/25 (0)
Were bone protection agents prescribed?		
Yes	1/27 (4)	5/25 (20)
No	26/27 (96)	20/25 (80)
Not applicable	0/27 (0)	0/25 (0)
Was ongoing nutritional supplementation recommended on discharge?		
Yes	48/86 (56)	38/72 (53)
No	35/86 (41)	30/72 (42)
Not applicable	3/86 (4)	4/72 (6)
Were arrangements made for follow-up by a dietitian?		
Yes	43/86 (50)	33/72 (46)
No	42/86 (49)	36/72 (50)
Not applicable	1/86 (1)	3/72 (4)
Yes, if ongoing nutritional supplementation recommended[#]	38/47 (81)	29/38 (76)
Was the patient on immunosuppressives on discharge?		
Yes	49/86 (57)	48/72 (67)
No	37/86 (43)	21/72 (29)
Not applicable	0/86 (0)	3/72 (4)
Was a plan for safety monitoring implemented?	35/49 (71)	34/48 (71)
Was there a plan for maintenance anti-TNF on discharge?		
Yes	27/86 (31)	29/72 (40)
No	58/86 (67)	32/72 (44)
Not applicable	1/86 (1)	11/72 (15)
Was a plan for safety monitoring implemented?	18/27 (67)	17/29 (59)
Patients discharged on oral steroids, immunosuppressive drugs or anti-TNF agents (derived)	65/86 (76)	-
Were psychological/behavioural factors identified to contribute to poor disease management (e.g., significant anxiety/depression leading to non-adherence)		
Yes	11/86 (13)	12/72 (17)
No	58/86 (67)	51/72 (71)
Unclear	17/86 (20)	9/72 (13)
If yes, was an outpatient plan put in place to help the patient address this?	8/11 (73)	8/12 (67)

Was the plan for follow-up documented in the discharge summary?	78/86 (91)	67/72 (93)
Was the discharge summary sent/faxed/emailed to the patient's general practitioner?		
Yes	76/86 (88)	62/72 (86)
No	5/86 (6)	4/72 (6)
Unclear	5/86 (6)	6/72 (8)
Patient had previous outpatient visits or private practice consultation for IBD		
Yes	62/87 (71)	51/75 (68)
No	22/87 (25)	21/75 (28)
Unclear	3/87 (3)	3/75 (4)
	N, Median, (Q1, Q3)	2014
Number of times patient seen in 12 months before start date of this admission	53, 3 (1, 4)	34, 3 (2, 6)
	n/N (%)	2014
Disease active at last OPD appointment or private practice review	40/62 (65)	22/51 (43)

Excludes 'N/A' (n=1)

Ulcerative colitis

Demographics

	2021	2014
Ulcerative colitis cases (total/site)	N = 99	N=69
	Mean (SD)	Mean (SD)
	12.3 (3.5)	13 (4.1)
Age on admission (years)	n/N (%)	n/N (%)
0-1	0/99 (0)	1/69 (1)
2-5	5/99 (5)	3/69 (4)
6-11	30/99 (30)	14/69 (20)
12-17	64/99 (65)	51/69 (74)
Gender		
Male	53/99 (54)	37/69 (54)
Female	45/99 (46)	32/69 (46)
Other	1/99 (1)	0/69 (0)
Primary reason for admission		
New diagnosis	21/99 (21)	14/69 (20)
Emergency admission	48/99 (48)	36/69 (52)
Planned admission (known case)	15/99 (15)	8/69 (12)
Elective admission for surgery	4/99 (4)	8/69 (12)
Transfer from another site	4/99 (4)	2/69 (3)
Other	7/99 (7)	1/69 (1)
Source of admission		
ED admission	58/99 (59)	39/69 (57)
Referred by GP	4/99 (4)	2/69 (3)
Advised to attend via IBD nurse helpline	7/99 (7)	0/69 (0)
Referred in from Hospital OPD	17/99 (17)	14/69 (20)
Referred in from GE specialist rooms	6/99 (6)	5/69 (7)
Referred in from surgical specialist rooms	2/99 (2)	4/69 (6)
Transfer from another site	11/99 (11)	8/69 (12)
Other	14/99 (14)	1/69 (1)
Has the patient had previous overnight admissions with UC in the two years prior to this admission at this hospital?	n/N (%)	n/N (%)
	48/99 (49)	35/69 (51)
	Median (Q1, Q3)	Median (Q1, Q3)
	1.0 (1.0, 3.0)	2 (1, 3)
	n/N (%)	n/N (%)
Has there been a UC-related admission within the last 30 days?	16/48 (33)	8/35 (23)
The patient was:		
Discharged home	98/99 (99)	67/69 (97)
Transferred to another centre for medical management	1/99 (1)	1/69 (0)

Discharged at own risk	0/99 (0)	0/69 (0)
Discharged to a nursing home or rehabilitation centre	0/99 (0)	0/69 (0)
Transferred to another centre for surgery	0/99 (0)	1/69 (0)
Deceased	0/99 (0)	0/69 (0)
Length of stay (days)	Mean (SD)	Mean (SD)
	5.4 (5.4)	10.2# (33.6)
	n/N (%)	n/N (%)
1-2	25/99 (25)	12 (17)
3-6	48/99 (49)	36 (52)
7-13	21/99 (21)	16 (23)
14-27	3/99 (3)	2 (3)
28+	2/99 (2)	3 (4)

Outlier (n=1) of 280 days.

Initial assessment during the first full day following admission

	2021 n/N (%)	2014 n/N (%)
Duration of disease stated in admission notes#	55/76 (72)	38/55 (69)
Duration of disease (years)#		
< 1	27/49 (55)	14/38 (37)
1 - <2	14/49 (29)	7/38 (18)
2 - <5	6/49 (12)	10/38 (26)
5 - <10	2/49 (4)*	7/38 (18)
Extent of colitis at the most recent assessment recorded in the admission notes #	47/76 (62)	23/55 (42)
UCUlcerative proctitis (E1)	3/47 (6)	-
UCLeft-sided UC (distal to splenic flexure) (E2)	7/47 (15)	-
UCExtensive (hepatic flexure distally) (E3)	5/47 (11)	-
UCPancolitis (proximal to hepatic flexure (E3)	27/47 (57)	-
UCNever severe* (S0)	5/47 (11)	-
UCEver severe* (S1)	8/47 (17)	-
UCIBD-U	1/47 (2)	2/23 (9)
UCUnknown	6/47 (13)	0/23 (0)
Disease activity severity recorded in the first 24 hours (e.g. PUCAI)	58/99 (59)	15/69 (22)
Recorded number of loose stools passed in the first full day following admission ##	82/93 (88)	45/60 (75)
Recorded number of bloody stools passed in the first full day following admission ###	74/92 (80)	38/59 (64)
Notes recorded the current presence of:		
Fevers	14/99 (14)	11/69 (16)
Presence of nocturnal stools	38/99 (38)	28/69 (41)
Presence of urgency or incontinence	23/99 (23)	17/69 (25)
Mouth ulcers	3/99 (3)	5/69 (7)
Arthralgia	8/99 (8)	2/69 (3)

Arthritis	4/99 (4)	1/69 (1)
Ankylosing spondylitis	0/99 (0)	0/69 (0)
Erythema nodosum	4/99 (4)	0/69 (0)
Pyoderma gangrenosum	0/99 (0)	0/69 (0)
Iritis	0/99 (0)	1/69 (1)
Anal fissure	2/99 (2)	1/69 (1)
Fistula	1/99 (1)	0/69 (0)
Abscess	0/99 (0)	0/69 (0)
Malnutrition	16/99 (16)	17/69 (25)

Excludes new diagnoses ## Excludes 'N/A' / stoma. ### Excludes 'N/A'.
*p<0.05

Comorbidity

	2021 n/N (%)	2014 n/N (%)
Were any significant comorbid diseases/conditions documented? (select all that apply)		
Yes	38/99 (38)	19/69 (28)
Statement that patient had no relevant comorbidities	8/99 (8)	26/69 (38)
None recorded	53/99 (54)	24/69 (35)
Comorbidities		
Cardiovascular	1/38 (3)	2/19 (11)
Respiratory	9/38 (24)	2/19 (11)
Renal	5/38 (13)	1/19 (5)
Diabetes	2/38 (5)	0/19 (0)
Liver disease	4/38 (11)	2/19 (11)
Active cancer	0/38 (0)	0/19 (0)
Iron deficiency anaemia	3/38 (8)	1/19 (5)
Psychological condition	10/38 (26)	2/19 (11)
Other	24/38 (63)	13/19 (68)

Medication on admission

	2021 n/N (%)	2014 n/N (%)
Was the patient taking treatment for ulcerative colitis on admission?		
Yes	65/99 (66)	43/69 (62)
No	32/99 (32)	24/69 (35)
Not stated	2/99 (2)	2/69 (3)
Treatment(s):		
Sulfasalazine	6/65 (9)	6/43 (14)
Oral 5-ASA	32/65 (49)	20/43 (47)
Topical 5-ASA	6/65 (9)	2/43 (5)
Oral corticosteroids	32/65 (49)	22/43 (51)
Topical corticosteroids	7/65 (11)	3/43 (7)
Mercaptopurine	5/65 (8)	3/43 (7)

Azathioprine	14/65 (22)**	20/43 (47)
Methotrexate	4/65 (6)	1/43 (2)
Antibiotics	3/65 (5)	2/43 (5)
Dietary therapy	0/65 (0)	1/43 (2)
Allopurinol	0/65 (0)	
Anti-TNF agent	21/65 (32)	5/43 (12)
Other (e.g. trial medication or Complementary medicine)	18/65 (28)	12/43 (28)
Estimate of compliance recorded	9/65 (14)	6/43 (14)

**p<0.01

Smoking status

	2021 n/N (%)	2014 n/N (%)
What was the smoking status of the patient?		
Not documented	87/99 (88)	52/69 (75)
Not currently smoking	12/99 (12)*	16/69 (23)
Current smoker	0/99 (0)	1/69 (1)

*p<0.05

Other assessment during admission

Prolonged steroid use

	2021 n/N (%)	2014 n/N (%)
In the 12 months prior to admission was the patient taking oral steroids for UC (at any time) for >3 months?	13/99 (13)	14/69 (20)
Was an appropriate dose reduction planned?	12/13 (92)	13/14 (93)
Was bone protection used?	5/13 (39)	3/14 (21)
Had a DEXA scan been done within 5 years?	0/13 (0)	1/14 (7)
What steroid-sparing strategies were tried?		
Thiopurine	9/13 (69)	12/14 (86)
Methotrexate	0/13 (0)	0/14 (0)
Anti-TNF agent	6/13 (46)	3/14 (21)
None	3/13 (23)	2/14 (14)
Other	3/13 (23)	1/14 (7)
Steroid-sparing strategy outcomes		
Thiopurine		
Ongoing steroid-sparing therapy	5/9 (56)	9/12 (75)
Successful steroid cessation	1/9 (11)	2/12 (17)
Stopped due to lack of clinical benefit	1/9 (11)	1/12 (8)
Other	2/9 (22)	0/12 (0)
Anti-TNF agent		
Ongoing steroid-sparing therapy	3/6 (50)	2/3 (67)
Successful steroid cessation	1/6 (17)	1/3 (33)
Other	2/6 (33)	0/3 (0)
Other steroid-sparing strategy		

Ongoing steroid-sparing therapy	1/3 (33)	1/1 (100)
Successful steroid cessation	1/3 (33)	0/1 (0)
Stopped due to lack of clinical benefit	1/3 (33)	0/1 (0)

Weight assessment and dietetic support during admission

	2021 n/N (%)	2014 n/N (%)
Was a dietetic assessment recorded?	29/99 (29)	23/69 (33)
Formal nutritional risk assessment documented in the patient record	8/99 (8)	9/69 (13)
Dietitian	7/8 (88)	7/9 (78)
Nurse	1/8 (13)	0/9 (0)
Patient's weight recorded within two days of admission	96/99 (97)	55/69 (80)
Patient's height recorded	41/99 (41)	28/66 (42)
Patient's weight recorded within two days of discharge	53/99 (54)	24/69 (35)
BMI recorded	37/99 (37)	20/69 (29)
Was it documented that a dietitian saw the patient?#	26/61 (43)	20/69 (29)
Was dietary treatment recommended?	23/99 (23)	22/69 (32)

Excludes 'N/A – well-nourished/not needed

Investigations

	2021 n/N (%)	2014 n/N (%)
Results recorded within 24 hours of admission:		
C-reactive protein (CRP)	88/99 (89)	60/69 (87)
Haematocrit	93/99 (94)	63/69 (91)
Haemoglobin	94/99 (95)	67/69 (97)
Albumin	86/99 (87)	61/69 (88)
Faecal calprotectin	38/99 (38)	15/69 (22)
Stool sample sent for stool culture/PCR within 48 hours of admission#	58/91 (64)	45/66 (68)
Stool culture/PCR positive	2/58 (3)	1/45 (2)
Stool sample sent for *Clostridium difficile* toxin within 48 hours of admission#	44/91 (48)	35/65 (54)
C. diff positive	3/44 (7)	1/35 (3)
Flexible sigmoidoscopy or colonoscopy carried out within 24 hours of admission in patients presenting with acute severe UC#	10/45 (22)	12/57 (21)
Flexible sigmoidoscopy or colonoscopy carried out between 24 to 72 hours of admission in patients presenting with acute severe UC#	11/34 (32)	13/45 (29)
Biopsies taken for histology	20/21 (95)	13/13 (100)
Biopsies taken for CMV	12/20 (60)	3/13 (23)
Imaging used during the admission		
No imaging performed	60/99 (61)	33/69 (48)
Abdominal X-ray	17/99 (17)*	22/69 (32)
Abdominal ultrasound (not small bowel specific)	17/99 (17)	11/69 (16)
Abdominal CT scan	4/99 (4)	5/69 (7)
Other	13/99 (13)	13/69 (19)

[#] Excludes 'N/A'
*p<0.05

Care team and ward

	2021 n/N (%)	2014 n/N (%)
Specialty responsible for the patient's care 24 hours after admission		
Acute or general medicine	2/99 (2)	-
Gastroenterology	1/99 (1)	-
Paediatric acute or general medicine	11/99 (11)	-
Paediatric colorectal surgery	1/99 (1)	-
Paediatric gastroenterology	81/99 (82)	-
Paediatric general surgery	1/99 (1)	-
Other	2/99 (2)	-
Paediatric gastroenterology consultant or paediatric registrar/fellow consulted		
Yes	93/97 (96)***	63/69 (91)
No	1/97 (1)*	4/69 (6)
Not required	3/97 (3)	1/69 (1)
Paediatric surgeon, paediatric colorectal surgeon, colorectal surgeon or respective registrars consulted		
Yes	11/94 (12)	25/69 (36)
No	20/94 (21)	27/69 (39)
Not required	63/94 (67)	15/69 (22)
IBD nurse specialist saw the patient during admission	15/99 (15)	16/69 (23)
Patient cared for on a specialist gastroenterology ward	72/99 (73)	20/69 (29)
Joint paediatric gastroenterology/surgical	2/72 (3)	-
Paediatric gastroenterology	59/72 (82)	-
Paediatric medical	11/72 (15)	-
Patient received short term psychological support Total [%] & w. psychological comorbidity [%]	33/99 (33) 5/5 (50)	17/69 (25) -
Psychologist	6/33 (18)	4/17 (24)
Psychiatrist	0/33 (0)	1/17 (6)
Social worker	21/33 (64)	11/17 (65)
Pastoral care	2/33 (6)	1/17 (6)
Other	14/33 (42)	4/17 (24)
Patient received short-term psychotropic medication [#]	2/87 (2)	1/67 (1)
Patient discussed at a multidisciplinary team meeting [##]	24/92 (26)	9/61 (15)

Excludes 'N/A' ## Excludes elective admissions
*p<0.05, ***p<0.001

Medical intervention
Use of antithrombotic therapy

	2021 n/N (%)	2014 n/N (%)
Was the patient given DVT/PE prophylaxis?		

Yes	10/99 (10)***	21/69 (30)
No	89/99 (90)	48/69 (70)
Patient had a thrombotic episode during admission	0/95 (100)	0/61 (0)

***p<0.001

Steroid and other therapy

	2021 n/N (%)	2014 n/N (%)
Were corticosteroids initiated during this admission?	66/91 (73)	47/61 (77)
IV	58/66 (88)	41/47 (87)
Oral	34/66 (52)	12/47 (26)
Topical	4/66 (6)	1/47 (2)
Other therapies started during the admission (if non-elective patient)		
None	25/91 (27)	25/61 (41)
5-Aminosalicylates	15/91 (16)	17/61 (28)
Thiopurine therapy	17/91 (19)	9/61 (15)
Methotrexate	4/91 (4)	0/61 (0)
Cyclosporin	0/91 (0)	0/61 (0)
Anti-TNF	14/91 (15)	8/61 (13)
Other nutrition support (e.g. EEN, supplemental nutrition, CDED, SCD, PEN)	4/91 (4)	-
Other	37/91 (41)	17/61 (28)

Surgical intervention

	2021 n/N (%)	2014 n/N (%)
Did the patient have surgery on this admission? (Yes)	5/99 (5)*	11/69 (16)
Was there a delay of more than 48 hours between decision to operate and surgery? (Yes, excludes unclear)	0/2 (0)	0/2 (0)
Was the ASA status recorded on an anaesthetic chart?	4/5 (80)	6/11 (55)
What was the status?		
1	0/4 (0)	0/6 (0)
2	2/4 (50)	5/6 (83)
3	2/4 (50)	1/6 (17)
4	0/4 (0)	0/6 (0)
Indications for surgery		
Failure of medical therapy	1/5 (20)	5/11 (45)
Toxic megacolon	0/5 (0)	0/11 (0)
Perforation	0/5 (0)	0/11 (0)
Abscess	0/5 (0)	0/11 (0)
Bleeding	0/5 (0)	3/11 (27)
Obstruction	0/5 (0)	0/11 (0)
Dysplasia	0/5 (0)	0/11 (0)
Cancer	0/5 (0)	0/11 (0)
Ileostomy formation	1/5 (20)	1/11 (9)

Stoma closure	0/5 (0)	1/11 (9)
Completion proctectomy	1/5 (20)	3/11 (27)
Other	3/5 (60)	1/11 (9)
Intervention type		
Proctocolectomy	0/5 (0)	2/11 (18)
Subtotal colectomy	1/5 (20)	3/11 (27)
Completion proctectomy	1/5 (20)	2/11 (18)
Anal anastomosis	0/5 (0)	5/11 (45)
Ileostomy	1/5 (20)	5/11 (45)
Revision stoma	0/5 (0)	2/11 (18)
Closure stoma	0/5 (0)	1/11 (9)
Abscess drainage	0/5 (0)	0/11 (0)
Adhesions division	0/5 (0)	1/11 (9)
Perineal procedure	0/5 (0)	0/11 (0)
Other	3/5 (60)	3/11 (27)
Surgery undertaken laparoscopically/laparoscopically assisted		
Yes	3/5 (60)	8/11 (73)
No	1/5 (20)	3/11 (27)
Unclear	1/5 (20)	0/11 (0)
Patient seen by a stomal therapy nurse during this admission #	3/3 (100)	11/11 (100)
Patient seen by a stomal therapy nurse prior to surgery #	3/3 (100)	7/11 (64)
Postoperative complications	1/5 (20)	4/11 (36)
Reoperation (for any reason)	0/5 (0)	0/11 (0)
Malnutrition	0/5 (0)	2/11 (18)
Clostridium difficile-associated diarrhoea (CDAD)	0/5 (0)	0/11 (0)
Respiratory	0/5 (0)	0/11 (0)
Cardiac	0/5 (0)	0/11 (0)
Total parenteral nutrition (TPN)	0/5 (0)	2/11 (18)
Ileus	0/5 (0)	1/11 (9)
Small bowel obstruction	1/5 (20)	0/11 (0)
Pulmonary embolus (PE)	0/5 (0)	0/11 (0)
Deep vein thrombosis (DVT)	0/5 (0)	0/11 (0)
Stoma complications	0/5 (0)	1/11 (9)
Anastomotic leakage	0/5 (0)	0/11 (0)
Intra abdominal abscess	0/5 (0)	0/11 (0)
Intra abdominal bleeding	0/5 (0)	0/11 (0)
Rectal stump complications	0/5 (0)	1/11 (9)
Wound infection	0/5 (0)	0/11 (0)
Other	0/5 (0)	1/11 (9)

Excludes strictureplasty, abscess drainage, perineal procedure, adhesion division, seton insertion, other.

*p<0.05

Anaemia

	2021 n/N (%)	2014 n/N (%)
Patient anaemic on admission		
Yes	45/99 (45)	29/69 (42)
No	46/99 (46)	37/69 (54)
Not recorded	8/99 (8)	3/69 (4)
Anaemia noted or commented on by the treating team		
Yes	40/45 (89)	20/29 (69)
No	5/45 (11)*	9/29 (31)
Was anaemia (at presentation or during hospitalization) due to iron deficiency?		
Yes	33/45 (73)	18/29 (62)
No	1/45 (2)	4/29 (14)
Other cause/uncertain	6/45 (13)	1/29 (3)
Not recorded	5/45 (11)	6/29 (21)
What treatment was administered for anaemia?		
No treatment administered	0/33 (0)	-
Oral iron	3/33 (9)	1/18 (6)
IV iron	27/33 (82)	11/18 (61)
Blood transfusion	6/33 (18)	4/18 (22)
Nutritional advice	2/33 (6)	1/18 (6)
Not recorded	0/33 (0)*	4/18 (22)

*p<0.05

Discharge arrangements

	2021 n/N (%)	2014 n/N (%)
Patient taking oral steroids on discharge		
Yes	78/98 (80)	49/67 (73)
No	20/98 (20)	18/67 (27)
Steroid reduction program stated on discharge		
Yes	59/78 (76)	38/49 (78)
No	13/78 (17)	11/49 (22)
Not applicable	6/78 (8)	0/49 (0)
Bone protection agents prescribed for patients taking steroids		
Yes	10/78 (13)	9/49 (18)
No	67/78 (86)	39/49 (80)
Not applicable	1/78 (1)	1/49 (2)
Ongoing nutritional supplementation recommended on discharge		
Yes	19/98 (19)	17/67 (25)
No	72/98 (73)	49/67 (73)
Not applicable	7/98 (7)	1/67 (1)
Arrangements for dietitian follow-up		

Yes	19/98 (19)	13/67 (19)
No	71/98 (72)	53/67 (79)
Not applicable	8/98 (8)	1/67 (1)
Patient taking immunosuppressive drugs on discharge		
Yes	60/98 (61)	34/67 (51)
No	38/98 (39)	33/67 (49)
Plan for immunosuppressive drug safety monitoring implemented	47/60 (78)	18/34 (53)
Plan for maintenance anti-TNF on discharge		
Yes	29/98 (30)	11/67 (16)
No	68/98 (69)	49/67 (73)
Not applicable	1/98 (1)	7/67 (10)
Plan for anti-TNF safety monitoring implemented	18/29 (62)	7/11 (64)
Patients discharged on oral steroids, immunosuppressive drugs or anti-TNF agents (derived)	87/98 (89)	
Psychological/behavioural factors identified to contribute to poor disease management		
Yes	10/29 (10)	6/67 (9)
No	69/98 (70)	55/67 (82)
Unclear	19/98 (19)	6/67 (9)
Outpatient psychological plan put in place	8/10 (80)	4/6 (67)
Plan for follow-up documented in the discharge summary	95/98 (97)	63/67 (94)
Discharge summary sent/faxed/emailed to the patient's general practitioner		
Yes	85/98 (87)	56/67 (84)
No	4/98 (4)	4/67 (6)
Unclear	9/98 (9)	7/67 (10)
Patient had previous outpatient visits or private practice consultation for IBD		
Yes	69/99 (70)	50/69 (72)
No	28/99 (28)	17/69 (25)
Unclear	2/99 (2)	2/69 (3)
	N, Median, (Q1, Q3)	2014
Number of times patient seen in 12 months before start date of this admission	51, 3 (2, 4)	4 (3, 5)
	2021 n/N (%)	**2014** n/N (%)
Disease active at last OPD appointment or private practice review	43/69 (62)	28/50 (56)

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