



My IBD Experience

**Australian inflammatory bowel disease
patient experience of health care**

Research Report 2018

**Inflammatory Bowel Disease
Quality of Care Program**



About CCA

Crohn's & Colitis Australia (CCA) is a not-for-profit organisation that supports 85,000 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.

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Executive Summary

What is our experience of care?

Crohn's disease and ulcerative colitis, collectively referred to as inflammatory bowel diseases (IBD) affect 85 000 Australians. IBD's are chronic gastrointestinal conditions that can be severely debilitating and are intermittent and recurring for most. Their onset is early in life, commonly 15-35 years, so people usually live with and have treatment for these conditions for decades. Total hospital and indirect costs related to IBD for 2012 in Australia were estimated to be \$2.7 billion.

To explore the quality of care for people with IBD CCA undertook an audit of 71 hospitals in 2016. It identified that generally care did not meet the national standards for this chronically unwell group and that mental health issues were prevalent and service access limited. This study sought to measure the quality of care through the patient experience to provide evidence for co-created improvement in care.

This online survey targeted all people over 16 years of age living with IBD through CCA membership, online forums and through hospital and other medical clinics and settings. The survey focused on the experience of health care for people living with IBD against established standards, their needs, attitudes toward and access to psychological services and the variation in patient experience of health care for people in different service environments.

This survey of 1024 participants throughout Australia identified important findings summarised in here in a number of themes.

"I have a lot of fatigue and anxiety since being diagnosed and often feel that I can't live my life to the fullest for my age."

We are often quite unwell and our disease is poorly managed

Echoing the findings of the IBD Audit, patients reported a high burden of disease. Participants had lived with the condition for a mean of 14.2 years, and had active disease at the time of survey (69.6% according to the Manitoba Index), indicating that for many, long term control of the disease was inadequate. More than a quarter (26.8%) had been admitted to hospital overnight in the previous twelve months, with three quarters of these (77.6%) being unplanned emergencies. Steroids were used by nearly 40% of participants, another indicator of poorly controlled disease.

"I would also like to see a multidisciplinary approach in the form that there is a dedicated IBD team, inclusive of: a specialist, IBD nurse, dietitian specialising in gastrointestinal disorders, psychologist. This way each healthcare professional is updated and aware of all current treatments and the patients situation."

We don't have access to multidisciplinary care that we want

Participants' IBD treatment was mostly managed over the previous year by private specialists (57%). Encouragingly, almost all had access to a gastroenterologist, but fewer had access to the minimum standard multidisciplinary team; IBD nurses (32.4%), dietitian (30.9%), pharmacists (26.1%) and psychologist (12%). Importantly, requests for access to the multidisciplinary team was the most common theme suggested to improve health care.

"In my treatment so far very little mention or advice on the impact on mental health aspects of this socially isolating disease has been made. Since diagnosis, work, family and social life have changed and contracted significantly to a point where I miss (and otherwise avoid) a lot of formerly enjoyable activities. If remission does not occur soon I wonder what my life will become."

A lot of us are distressed but we are not routinely assessed and lack access to services

The study confirmed the high prevalence of psychological distress (50% reporting some distress). Consistent with the IBD Audit, few were seeing a psychologist (15.2%). Despite the higher frequency of distress reported, the survey found only 16.1% of participants reported being asked about their mental health by their specialist or IBD Nurse, and of those not asked, 56% would

have liked to have been asked. This was reinforced in qualitative themes requesting more mental health assessment, support and holistic (not just gastrointestinal) approach to their care. Those distressed were three times more likely to use opioids and psychotropics than those without distress, more commonly reported pain (63% vs 26%) and fatigue (84% vs 42%). The need to better assess mental health and address distress is apparent.

When our health worsens there are supports missing that would prevent us needing hospitalisation

The recurring nature of the diseases did not appear to be well managed in a chronic disease model of care. When experiencing a relapse, a third of participants had to wait more than 14 days to see a specialist. Only 55.4% had access to a helpline for advice regarding the relapse and half had a plan of what to do if they deteriorated. The high emergency hospital admission rates could be partly explained by this data.

"Just to have someone who knows what I'm going through, who is knowledgeable in IBD and can offer advice, a shoulder, help, guidance, treatment advice, understanding when I actually need it, not the next day or week or month."

We have treatment options, we need better information to understand them, and a say in the plan

While most participants reported they had their care and treatment explained, the quality of information and involvement in decision making varied. Medical specialists (48.7%) and IBD nurses (48%) provided complete information more commonly than GPs (20.5%), dietitians (28.5%), pharmacists (15.4%) or emergency department staff (8.7%). Nearly two thirds of participants had a choice in their treatments, but 51% wanted to be more involved in decisions about their care.

"I have also never had a suggestion that someone like an IBD nurse even existed, and certainly no contact/suggestion about psych support or a dietitian."

The setting where you receive IBD healthcare can limit your access to important services

There were some differences in the experience of care according to outpatient management setting and IBD nurse access. While public IBD specific clinics only managed 19% of participants, they provide substantially better access to IBD nurses (83.7%) and responsive helplines (80.7%). Participants in other settings such as public outpatient clinic, private specialist and GP managed care were less likely to have access to IBD nurses and helplines that are integral to effective chronic disease management models of care. IBD specific clinics also provided better access to research trials (37% vs next best public outpatients 21%). Those managed by private specialists (84%) were more confident that their GP is kept informed about their management which was reported as a common theme to improve care.

"I think all patients with IBD should have firm written plan of action that they, their GP, specialist, pharmacist (and maybe dietitian) all agree to and can put into action when needed."

Background

IBD affects over five million people worldwideⁱ, with the overall incidence rate in Australia of 29.3 per 100,000 peopleⁱⁱ. People living with IBD can suffer chronic pain, bloody diarrhoea with frequent bowel movements up to 20-30 times a day, weight loss, anaemia and fatigue, significantly impairing their everyday functioning. The chronic and relapsing nature of the condition and common onset between the ages of 15-35 years mean that young people can be impacted during a time of social and emotional development. Healthcare costs, productivity losses and other indirect costs were estimated to be over \$2.7 billionⁱⁱⁱ for the Australian public in 2012.

A national audit of IBD hospital care led by Crohn's & Colitis Australia (CCA)^{iv} in 2016 found that care fell short of the Australian IBD Standards^v: inconsistent access to multidisciplinary services, and important processes of care were lacking. Psychological conditions were the most frequently occurring comorbidity, yet less than a quarter of those received psychological support and less than 5% of sites had a mental health clinician in their team. Hospitals with multidisciplinary IBD services demonstrated improved care in important areas. The audit established expectations and evidence for funders, policy makers, clinicians and organisations to improve the quality of IBD care. The data was gathered from hospital and clinician based information systems. To complement this, an understanding of the variability in care from the patient perspective is required. Patient centred care^{vi} and consumer co-creation in health^{vii} have been shown to improve the safety and quality of health care.

CCA commenced a two-stage project to study the experience of healthcare of people living with IBD. Stage one was undertaken in 2017 and utilised the Consumer Health Forum 'Real People Real Data Toolkit'^{viii} to collect and analyse patient stories to develop practical evidence. The issues and themes identified in this study^{ix} were used to inform stage two of the project – a quantitative national survey of patient experience as it relates to the Australian IBD Standards, with a focus on the prevalent mental health issues for people living with IBD. This report describes the methodology and findings of the national survey of patient experience.

Aims of the project

To our knowledge this is the first Australian national study exploring the patient experience of healthcare for people living with IBD. The specific aims of the study were as follows:

- To assess the experience of health care for people living with IBD against established standards
- To describe the needs, attitudes toward and access to psychological services for people with IBD
- To compare the patient experience of health care for people in different service environments.



Methodology

This exploratory survey examined the research question: *What is the patient experience of health care for inflammatory bowel disease in Australia?* The study was conducted as an online cross-sectional survey.

Survey tool

A questionnaire was developed incorporating newly designed questions relating to the Australian IBD Standards 2016 and existing validated tools: IBD Control survey (IBD-Control-8)^x, Manitoba index^{xi}, PRO3 for Crohn's disease^{xii}, PRO2 for ulcerative colitis^{xiii}, Kessler Psychological Distress Scale (K10)^{xiv} and some Picker Patient Experience Questionnaire (partial)^{xv}.

The questionnaire was transferred to an electronic web-based format using the Qualtrics online research software. The online tool was trialled by a small number of researchers and consumers and revised prior to commencement of data collection.

Eligibility

All people diagnosed with Crohn's disease, ulcerative colitis, or indeterminate colitis aged 16 or above were eligible to participate in the survey. Participants were required to:

- Be able to answer the questionnaire in English.
- Receive their health care in Australia
- Complete the survey only once

Only those with an experience of inpatient hospital care in the previous 12 months were required to complete the inpatient section of the survey.

Recruitment

Recruitment of participants was promoted through two paths:

- CCA membership and associated social media including other IBD related networks.
- Advertising through public and private gastroenterology and other medical clinics and practices throughout Australia and the Royal Flying Doctor Service, using various flyers, newsletters and electronic media at sites.

Data collection

The survey was open to participants between 20 June and 8 August 2018.

Potential participants were invited to follow an online link to the Plain Language Statement explaining the terms of participation and clarifying that completion of the survey implied consent. Respondents were asked to provide responses reflecting on their healthcare over the previous 12 months unless otherwise directed. Participants were able to save their responses and access the survey as many times as they required before the closing date.

Data analysis

The data collected using Qualtrics was cleaned and exported for analysis using Microsoft Excel and SPSS.

A large chunk of the analysis was descriptive, where means (SD)/medians (IQR) and frequencies (%) were used to describe the sample. Independent student t-test, one-way ANOVA (or non-parametric equivalents) and chi-square test were used to compare patient experience of health care for people in different service environments (e.g. healthcare setting). Qualitative data reviewed using simple content analysis.

Governance and Ethics

The Australian IBD Patient Experience Survey functioned under the auspices of CCA and its Board. The Board was assisted in its task by the Patient Experience Survey Advisory Committee (PESAC) see p2. The PESAC had responsibility for providing guidance and advice to CCA in order to deliver the objectives of the project.

CCA provided project support to the PESAC. The PESAC and CCA staff maintained relevant privacy, confidentiality and security requirements in line with CCA policy and NHMRC guidelines.

The study was approved by the Human Ethics Advisory Group, Faculty of Health, Deakin University, approval number: HEAG-H 85_2018.

Findings

1. Study sample

Overall, 1024 respondents accessed the survey. Of these, 264 did not progress beyond the initial questions, further 22 progressed with fewer than 50% of questions (and typically only completed some demographics). These 286 incomplete cases were removed from further analysis. Three respondents stated they had neither CD, UC nor IC and were removed from the analysis. Four respondents were younger than 16 years old and were removed from further analysis. The final analysis was therefore conducted using 731 cases.

2. Demographics

All respondents confirmed that they live and receive their healthcare in Australia. The respondents were mainly female (71.5%), university-educated (45.9%), married/de facto (65.1%), employed full-time (34.1%), speaking English at home (98.2%) and current members of the CCA (63.1%). The majority of respondents resided in the major Australian cities* (71.4%), with just one per cent residing in remote or very remote areas of Australia (**Table 1**). Respondents came from each State and Territory, predominantly New South Wales, Victoria or Queensland (81%) (**Figure 1**) and representation was proportionately similar to the general population for each jurisdiction.

Table 1 Demographic characteristics

		IBD (n=731)
Age, mean (SD), range (in years)		46.5 (15.5), 16-84
Sex, n (%)	Female	523 (71.5)
	Male	206 (28.2)
	Other	2 (0.3)
Education, n (%)	< Year 12	104 (14.2)
	Year 12	128 (17.5)
	Vocational/TAFE	123 (16.8)
	Bachelor degree	255 (34.9)
	Master degree	67 (9.2)
	PhD/doctorate	13 (1.8)
	Other (diploma/certificate)	41 (5.6)
Marital status, n (%)	Single (never married)	175 (23.9)
	Married/de facto	476 (65.1)
	Widowed	16 (2.2)
	Divorced	42 (5.7)
	Separated	19 (2.6)
	Other	3 (0.4)
Employment, n (%)	Full time	249 (34.1)
	Part time	158 (21.6)
	Unemployed and currently looking for work	16 (2.2)
	Unemployed and currently not looking for work	17 (2.3)
	Student	55 (7.5)
	Retired	107 (14.6)
	Homemaker	28 (3.8)
	Self-employed	42 (5.7)
	Unable to work	48 (6.6)
	Other	11 (1.5)
Language, n (%)	English	718 (98.2)
Location [^] , n (%)	Major cities of Australia	522 (71.5)
	Inner regional Australia	155 (21.2)
	Outer regional Australia	45 (6.2)
	Remote/very Remote	8 (1.1)
Current member of Crohn's & Colitis Australia		461 (63.1)

[^] missing n=1, * remoteness categories defined according to the Australian Statistical Geography Standard (ASGS) Volume 5 - Remoteness Structure (cat. no. 1270.0.55.005) publication

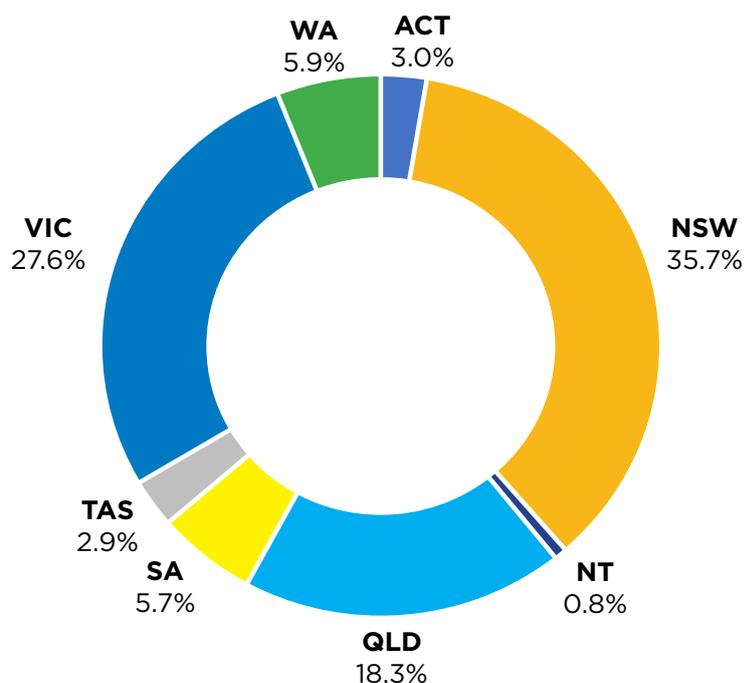


Figure 1 Survey participation by state (in %)

3. Clinical characteristics

There was a slight predominance of respondents with CD (57.6%) (**Table 2**). Disease duration was on average 14.2 years.

Self-reported disease activity varied depending on the instrument used but was predominantly “mildly to moderately” active. According to the Manitoba Index, a single-item indicator of disease activity over an extended time, most participants (69.6%) had active IBD. According to the patient reported outcome measure for Crohn’s disease, PRO3, 57.4% of respondents had active disease, and PRO2 for ulcerative colitis, 55.1% of respondents had active disease. According to IBD-Control-8, a patient reported disease control measure, 63.2% had active IBD while according to the IBD-Control-VAS, 60.3% had active IBD.

Table 2 Clinical characteristics

		IBD (n=731)
IBD type, n (%)	Crohn’s disease	421 (57.6)
	Ulcerative colitis	287 (39.3)
	Indeterminate colitis	23 (3.1)
Disease duration, mean (SD), range (in years)		14.2 (11.5), 1-63
Stoma, n (%)		41 (5.6)
Fistula, n (%)		47 (6.4)
Perianal disease, n (%)		51 (7)
Manitoba Index, n (%)	Inactive IBD	222 (30.4)
	Active IBD	509 (69.6)
Manitoba index subcategories, n (%)	Constantly active, giving me symptoms every day	111 (15.2)
	Often active, giving me symptoms most days	140 (19.2)
	Sometimes active, giving me symptoms on some days (for instance 1 – 2 days/week)	156 (21.3)
	Occasionally active, giving me symptoms 1 – 2 days/month	102 (14)
	Rarely active, giving me symptoms on a few days in the past 3 months	90 (12.3)
	I was well in the past 3 months, what I consider a remission or absence of symptoms	132 (18.1)
PRO3* (CD respondents only n=421), n (%)	Inactive CD	179 (42.6)
	Mildly active CD	107 (25.5)
	Moderately active CD	123 (29.3)
	Severely active CD	11 (2.6)

Table 2 Clinical characteristics (continued)

		IBD (n=731)
PRO2 (UC respondents only, n=287), n (%)	Inactive IBD (0 bleeding plus stools <=2)	129 (44.9)
	Active IBD (bleeding >= 1 and/or stools >2)	158 (55.1)
IBD-control-8, n (%)	Inactive IBD (>=13)	269 (36.8)
	Active IBD (<13)	462 (63.2)
IBD-control-8, mean (SD)	Range 0-16, with 0 meaning worst control	9.8 (4.9)
IBD-Control-VAS, n (%)	Inactive IBD (>=85)	290 (39.7)
	Active IBD	441 (60.3)
IBD-Control-VAS, mean (SD)	Range 0-100, with 0 meaning worst control	71.9 (25.5)

^ missing n=1

4. IBD healthcare satisfaction and setting

Patient experience is the focus of this survey and differs from satisfaction measures as described in the section 'Important Findings'. Nevertheless a single general satisfaction question was included. The majority of respondents (74.8%) were satisfied with the IBD healthcare they receive (**Table 3**).

Table 3 Satisfaction with IBD healthcare, n (%)

	IBD (n=731)
Very satisfied	258 (35.3)
Satisfied	289 (39.5)
Neither satisfied nor dissatisfied	112 (15.3)
Dissatisfied	63 (8.6)
Very dissatisfied	9 (1.2)

Most respondents received their IBD care from private practitioners (**Figure 2**).

In the last 12 months, my IBD has been managed mostly by:

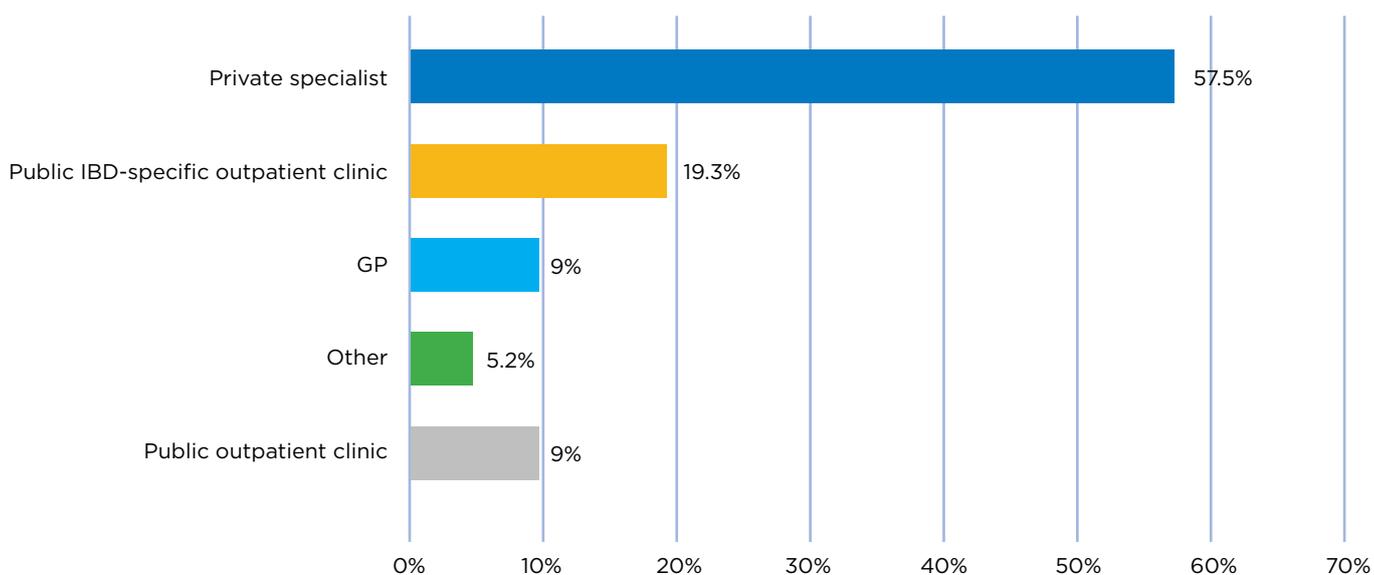


Figure 2 Setting where IBD is managed



More than a quarter (26.8%) of respondents had an overnight inpatient hospital stay in the previous year and close to 78% of these were emergency or unplanned admissions (**Figure 3**).

Have you had an overnight, in-hospital stay for your IBD in the last year?

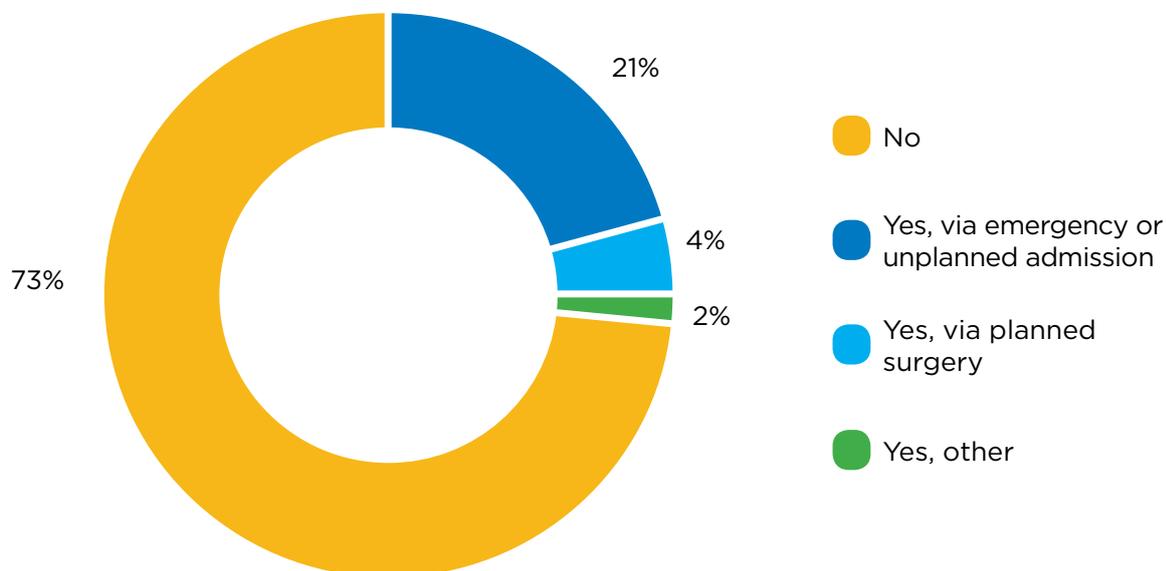


Figure 3 Overnight inpatient admissions

5. Measuring patient experience against the Australian IBD Standards

In this section survey results are presented as they relate to the Australian IBD Standards 2016.

Standard A: High-quality clinical care

A1 The IBD team & A2 Essential Supporting Services

The IBD team available to these respondents included gastroenterologists (97%), and less frequently an IBD nurse (32.4%), dietitian (30.9%), colorectal surgeon (26.3%) and pharmacist (26.1%). Very few patients had access to psychologists (12%) and stoma nurses (10.3%) (**Figure 4**).

Which specialists are available to you in your IBD treating team?

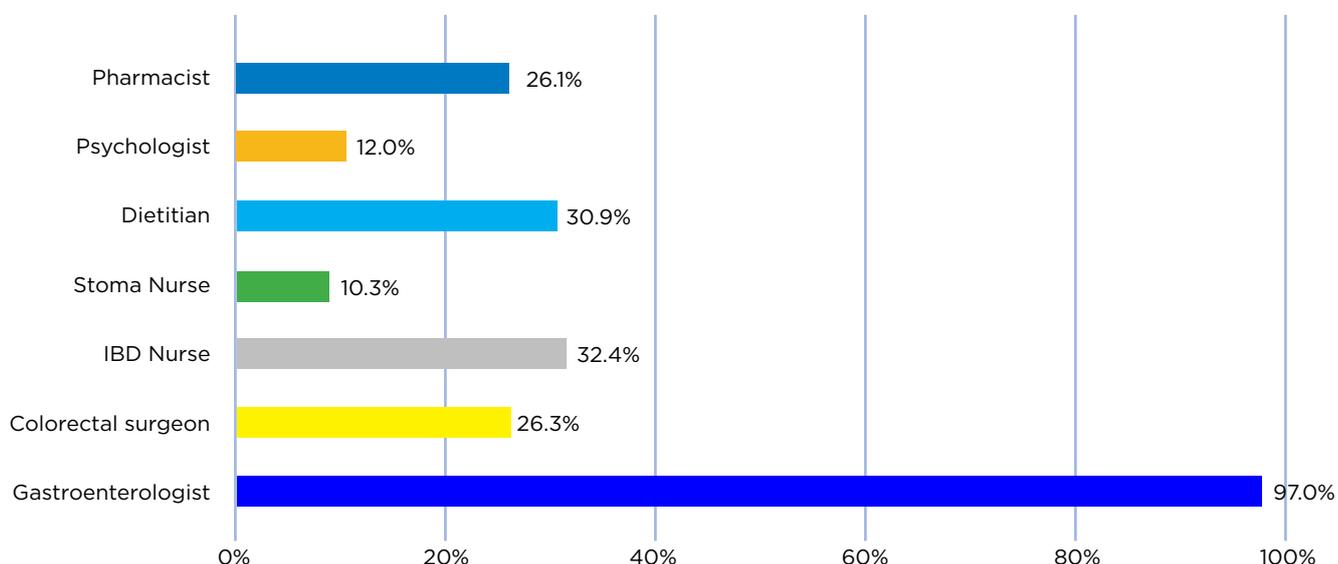


Figure 4 Specialists available in the IBD team

Respondents managed by Public IBD Outpatient Clinics reported the highest access to IBD nurses (83.7%), dietitians (48.9%) and stoma nurses (20.6%) (see Appendix 1).

Selected medication use was surveyed in relation to IBD team prescribers. Overall, 39.9% of respondents had taken steroids for more than six weeks in the last year, 45.3% were currently taking immunomodulators and 38.7% took biologics, 9% took opiates and 18.3% took psychotropics (**Table 4**). Gastroenterologists were the most common prescribers of each medication other than psychotropics which were most commonly prescribed by GPs. For 72.3%, short- and long-term side effects of steroids were explained.

Table 4 Medication use and prescribers

		N (%)	Prescriber n (%)
Have you been taking steroid medication in the last year for more than six weeks?	Yes, but I'm no longer taking them	193 (26.4)	Gastroenterologist - 251 (34.3) GP - 22 (3) Other# - 19 (2.6)
	Yes, I am currently taking them	99 (13.5)	
	No	431 (59)	
	Unsure	8 (1.1)	
Have you been taking immunomodulator medication in the last year for more than six weeks?	Yes, but I'm no longer taking them	78 (10.7)	Gastroenterologist - 393 (53.8) GP - 5 (0.7) Other## - 11 (1.5)
	Yes, I am currently taking them	331 (45.3)	
	No	302 (41.3)	
	Unsure	19 (2.6)	
Have you been taking biologic medication in the last year for more than six weeks?	Yes, but I'm no longer taking them	29 (4)	Gastroenterologist - 300 (41) GP - 1 (0.1) Other### - 9 (1.2)
	Yes, I am currently taking them	283 (38.7)	
	No	400 (54.7)	
	Unsure	19 (2.6)	
Have you been taking opiate medication in the last year for more than six weeks?	Yes, but I'm no longer taking them	49 (6.7)	Gastroenterologist - 34 (4.7) GP - 62 (8.5) Other#### - 20 (2.7)
	Yes, I am currently taking them	67 (9.2)	
	No	605 (82.8)	
	Unsure	8 (1.1)	
Have you been taking psychotropic medication in the last year for more than six weeks?	Yes, but I'm no longer taking them	23 (3.1)	GP - 117 (16) Psychiatrist - 28 (3.8) Gastroenterologist - 9 (1.2) Other##### - 3 (0.4)
	Yes, I am currently taking them	134 (18.3)	
	No	565 (77.3)	
	Unsure	8 (1.1)	

Other included dermatologists, hematologists, hepatologists, rheumatologists, and other doctors (specialty unknown)

Other included rheumatologists, dermatologists, and other doctors (specialty unknown)

Other included rheumatologists and dermatologists

Other included colorectal surgeons, chronic pain service, emergency doctor, neurologist, rheumatologist, oncologists and other doctors (specialty unknown)

Other included a neurologist, a pain specialist and a rheumatologist



A5 Access to nutritional support and therapy

Overall, 30.9% of respondents had access to a dietitian. For inpatients, 38.3% were seen by a dietitian whilst in hospital (see A8/A10).

A6 Arrangements for the use of biological therapies (includes medication)

Biologics were being taken by 38.7% of respondents and a further 4% had taken them in the last year but ceased. These were prescribed by gastroenterologists predominantly, with a small number by rheumatologists or dermatologists (Table 4).

A8 Inpatient facilities & A10 Inpatient care

About a quarter of respondents had an in-hospital stay in the last year and for the majority of those (77.6%) (Figure 3) this was an unplanned admission. Inpatient facilities and services varied (Table 5). For the minority (30.1%), their bed was situated in the gastroenterology ward. Toilet facilities were seen as adequate by 71.4% of those who had a hospital stay. However, very few were seen by a dietitian or an IBD nurse in hospital (38.3% and 24.5%, respectively). Most had their important questions answered by the doctor or a nurse while staying in a hospital (84.7% and 80.6%, respectively). Very few (35.7%) who had surgery received what they regarded as adequate information before the procedure. The majority were informed about the medications they need to take following their admission and about the possible side-effects (80.1% and 60.2%, respectively). In many cases (47.4%), family/friends of the IBD patient hospitalized were informed about how to help them recover.

Only a minority (18.4%) were asked about their mental health concerns while staying in a hospital and fewer than 1% of respondents received mental health support while hospitalised. Overall, 93.9% of respondents felt they were treated with respect while hospitalised.

Table 5 Inpatient facilities and care

		IBD (n=196)
		n (%)
A8 Was your bed situated in a gastroenterology ward?	Yes	59 (30.1)
A8 Were the toilet facilities adequate for your needs and privacy?	Yes	140 (71.4)
A10 Were you seen by a dietitian?	Yes	75 (38.3)
A10 Were you seen by an IBD specialist nurse?	Yes	48 (24.5)
A10 Overall, did you feel you were treated with respect and dignity while you were in hospital?	Yes, always	119 (60.7)
	Yes, sometimes	65 (33.2)
	No	12 (6.1)

Further data on inpatient care as it relates to other standards is represented in Appendix 3

A9 Access to diagnostic services

Most respondents (74.1%) had chosen to have a colonoscopy through the private healthcare system and half of them (50.3%) did this to expedite the procedure (Table 6).

Table 6 Colonoscopy through the private system

		IBD (n=731)
		n (%)
A9 Have you ever chosen to have a colonoscopy or surgical treatment for your IBD through the private system?	Yes	542 (74.1)
Was it because you could receive treatment sooner?	Yes	368 (50.3)

A11 Outpatient care

The majority of respondents (81.9%) are reviewed for their IBD at least once a year but IBD helpline (includes direct contact with specialists) is available to just over 50% of respondents (**Table 7**). It took more than 14 days for 30.8% of participants to get to see their specialist when experiencing relapse.

Table 7 Outpatient care

		IBD (n=731)
		n (%)
A11 Is there a plan for your IBD to be reviewed at least once per year even if you are well?	Yes	599 (81.9)
	No	85 (11.6)
	Unsure	45 (6.2)
A11 Last time you had a relapse of your IBD, how long did it take to get to see your specialist?	1-2 days	156 (21.3)
	3-5 days	160 (21.9)
	6-14 days	188 (25.7)
	More than 14 days	225 (30.8)
A11 C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	Yes	405 (55.4)
	No	196 (26.8)
	Unsure	128 (17.5)

A13 Psychological care

The mean level of distress for these respondents was within the mild distress category, with 50% of respondents reporting good mental health (i.e. no distress) (**Table 8**). Overall, 15.2% of the respondents reported currently seeing a mental health practitioner and for the majority of those respondents this was a psychologist (n=81). The typical frequency of visits at a mental health practitioner was less often than once a month. Overall, 73% of those accessing mental health practitioners were satisfied with the treatment received. Only 16.1% of respondents were asked about their mental health by their specialist or IBD Nurse and 56% of those not asked would have liked to be asked. Overall, 64.6% of the respondents would like their gastroenterologist or IBD nurse to ask about any mental health concerns.

Just 12.2% reported access to a mental health practitioner as part of their IBD service, with 58.9% agreeing or strongly agreeing that having access to a mental health expert (i.e., psychologist, psychiatrist) is an important part of managing their IBD. Only 33.6% of respondents believed that accessing mental health services (i.e., psychologist, psychiatrist) was easy to arrange. Nearly 60% would have found it easy to talk to their GP about seeking mental health support while 43.2% would or have found it easy to discuss mental health with a gastroenterologist/IBD nurse.

Table 8 Mental health characteristics and mental healthcare

		IBD (n=731)
K10, mean (SD)		20.9 (8.2)
K10 ¹ , n (%)	Likely well (score 10-19)	369 (50.5)
	Likely mild distress (score 20-24)	135 (18.5)
	Likely moderate distress (score 25-29)	96 (13.1)
	Likely severe distress (score 30-50)	110 (15)
Are you seeing anyone currently for any mental health issues/stress? ²	Yes	111 (15.2)
	Seeing a Psychiatrist	19 (2.6)
	Seeing a Psychologist	81 (11.1)
	Seeing a GP	45 (6.2)
	Seeing a Nurse	1 (0.1)
	Seeing a Counsellor	8 (1.1)
	Seeing a Social Worker	2 (0.3)
Seeing CAMs therapist	2 (0.3)	

Table 8 Mental health characteristics and mental healthcare (continued)

		IBD (n=731)
If you are seeing a mental health expert, how often do you meet?	Weekly	9 (8.1)
	Fortnightly	17 (15.3)
	Once a month	36 (32.4)
	Less often than once a month	49 (44.1)
Are you satisfied with the treatment for your mental health issues?	Yes	81 (73)
While meeting with your Gastroenterologist or IBD nurse in the past 12 months, have you been asked about any mental health concerns (even if not related to your IBD)? ³	Yes	118 (16.1)
If not asked, would you have liked to be asked about any mental health issues? ⁴	Yes	322 (56)
Do you have access to a mental health expert (i.e., psychologist, psychiatrist) as part of your IBD service? ⁵	Yes	89 (12.2)
I believe having access to a mental health expert (i.e., psychologist, psychiatrist) is an important part of managing my IBD ⁵	Strongly agree	229 (31.3)
	Agree	202 (27.6)
	Neither agree nor disagree	243 (33.2)
	Disagree	34 (4.7)
	Strongly disagree	13 (1.8)
I would like my Gastroenterologist or IBD nurse to ask about any mental health concerns (even if not related to my IBD) ⁵	Yes	472 (64.6)
I believe accessing mental health services (i.e., psychologist, psychiatrist) is easy to arrange ⁵	Strongly agree	53 (7.3)
	Agree	192 (26.3)
	Neither agree nor disagree	310 (42.4)
	Disagree	128 (17.5)
	Strongly disagree	38 (5.2)
I have found it easy (or would find it easy) to talk to my GP about seeking mental health support ⁵	Strongly agree	180 (24.6)
	Agree	258 (35.3)
	Neither agree nor disagree	193 (26.4)
	Disagree	74 (10.1)
	Strongly disagree	16 (2.2)
I have found it easy (or would find it easy) to talk to my Gastroenterologist/IBD nurse about seeking mental health support ⁵	Strongly agree	104 (14.2)
	Agree	212 (29)
	Neither agree nor disagree	252 (34.5)
	Disagree	123 (16.8)
	Strongly disagree	30 (4.1)

¹ missing n=21 (2.9%), ² missing n=7 (1%), ³ missing n=8, ⁴ missing n=156, ⁵ missing n=10

Those with psychological distress were less satisfied with their IBD care (**Table 9**). They more commonly had an active disease (on symptom-based instruments), fistula or perianal disease, and were more commonly receiving steroids, opioids or antidepressants. Those distressed more commonly reported having been hospitalized for their IBD, more commonly reported pain or fatigue. Those distressed would have liked to be asked about their mental health by their gastroenterology team, less commonly had a plan of their IBD being reviewed annually or reported that their care was explained to them.

Table 9 Distress vs no distress

		K10 no distress n=368	K10 distress n=340
Are you satisfied with your IBD care?	Yes	314 (85.1)***	217 (63.6)
Manitoba Index	Active IBD	206 (55.8)***	289 (84.8)
Have a stoma		24 (6.5)	14 (4.1)
Have a fistula		18 (4.9)*	28 (8.2)
Have a perianal disease		17 (4.6)**	33 (9.7)
Currently taking steroids		34 (9.2)***	62 (18.2)
Currently taking opioids		19 (5.2)***	47 (13.8)
Currently taking psychotropics		40 (10.9)***	92 (27)
Have you had an over-night hospital stay for your IBD in the last 12 months?	Yes	82 (22.2)***	107 (31.4)
Suffer from significant pain or discomfort?	Yes	99 (26.8)***	216 (63.3)
Often feel lacking in energy (fatigued) (by 'often' we mean more than half of the time)?	Yes	155 (42)***	287 (84.2)
While meeting with your Gastroenterologist or IBD nurse in the past 12 months, have you been asked about any mental health concerns (even if not related to your IBD)?	No	299 (81)	266 (78)
If no, would you have liked to be asked about any mental health issues?	Yes	120 (40.1)***	62.4 (74.8)
Is there a plan for your IBD to be reviewed at least once per year even if you are well?	Yes	318 (86.2)**	266 (78)
Has a member of your treatment team explained your care and treatment options?	Yes, completely	203 (55)***	132 (38.7)

* p<0.05, **p<0.01, ***p<0.001

Only, 31.8% of those with severe distress were currently seeing a mental health practitioner (**Table 10**).

Table 10 Mental health engagement by distress level

		No distress n=369	Mild distress n=135	Moderate distress n=96	Severe distress n=110
Are you seeing anyone currently for any mental health issues/ stress?	Yes	29 (7.9)	28 (20.7)	18 (18.8)	35 (31.8)***

***p<0.001



A14 General practice communication (see Standard B1)

Standard B: Local delivery of care

B1 Arrangements for shared-care (including A14 General Practice communication)

For the majority of respondents (69.8%), their GP is involved in their IBD care, with 26% of respondents not confident which issues to consult with their GP and which with their specialist (**Table 11**). Overall, 76.1% reported that their GP was kept up-to-date regarding their treatment by the specialist/hospital.

Table 11 GP shared care

		IBD (n=731)
		n (%)
B1 Is your GP involved in your IBD care?	Yes	510 (69.8)
	No	186 (25.4)
	Unsure	33 (4.5)
B1 If your GP is involved in your IBD care, are you clear on what issues you should seek specialist/hospital care for?	Yes	375 (73.5)
	No	71 (13.9)
	Unsure	62 (12.1)
B1 Do you think your GP is kept informed about your results and treatment by your specialist/hospital?	Yes	556 (76.1)
	No	73 (10)
	Unsure	98 (13.4)

Those with access to an IBD nurse more commonly were clear regarding which issues are to be discussed with whom (82.4%) compared with those without access to an IBD nurse (69.5%) (see Appendix 2). Respondents managed by a private specialist were more confident that their GP is kept informed about their treatment/results (84%) compared with those managed by their GP (67.7%) or public IBD clinic (67.1%) (see Appendix 1).

Standard C: Maintaining a patient-centred service

C2 Rapid access to specialist advice

C3 Supporting patients to exercise choice between treatments

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

C5 involvement of patients in service improvement

IBD helpline was available to just over 50% of respondents (**Table 12**). Overall, 63.1% feel they have a choice in their treatment, but 51% would like to be more involved in decisions about their care and treatment.

Approximately one third of the respondents use complementary and alternative therapies (CAMs) and only about 30% doctors ask about CAMs use. Overall, 44.3% of the respondents have not been given a choice on how to participate in follow up care, but are happy with the way follow up care is delivered. Most participants (75.2%) have never been asked for feedback about their IBD care.

Table 12 Patient-centred services

		IBD (n=731)
		n (%)
C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	Yes	405 (55.4)
	No	196 (26.8)
	Unsure	128 (17.5)
C3 Do you have a choice in what treatment you have?	Yes	461 (63.1)
	No	64 (8.8)
	Unsure/I've never asked	123 (16.8)
	I'd rather the doctor decided	77 (10.5)
C2 Did you want to be more involved in decisions about your care and treatment?	Yes	373 (51)
	No	222 (30.4)
	Unsure	130 (17.8)
C3 Do you use any complementary therapies?	Yes	239 (32.7)
	No	441 (60.3)
	Unsure	45 (6.2)
C3 Does your doctor ask what complementary therapies you use, if any?	Yes	222 (30.4)
	No	439 (60.1)
	Unsure	64 (8.8)
C4 Have you been given a choice on how you participate in follow up care, e.g. specialist rooms, outpatient clinic or GP shared care?	Yes	177 (24.2)
	No, I'd like a choice	147 (20.1)
	No, but I'm happy with the way follow up care is delivered	324 (44.3)
	Unsure	77 (10.5)
C5 Have you ever been asked for feedback about your IBD care such as a survey, feedback card, web form, open day?	Yes	130 (17.8)
	No	550 (75.2)
	Unsure	45 (6.2)

Those with access to IBD nurse more commonly had access to IBD helplines (77.1%) than those without access (45.2%), choice in treatment (70.6% vs 60.2) and to be asked for feedback (32.3% vs 10.9%). They less commonly used complementary therapies (26%) than those without access to an IBD nurse (36.5) (see Appendix 2). Respondents managed by a private specialist most commonly used complementary therapies (35.9%) compared to public outpatients (24.2%), public IBD clinic patients (25%) and GP managed patients (28.1%) (see Appendix 1).

Standard D: Patient education and Support

D1 Provision of Information

Most participants (87%) had their care and treatment options explained to them (**Table 13**). In 48% of cases, the treating team provided an opportunity for the respondent's family/carer to be involved in education/information sharing. Overall, 72.1% received printed information about IBD and 49.8% had a plan of what to do if their condition deteriorated.

Table 13 Provision of information

		IBD (n=731)
		n (%)
D1 Has a member of your treatment team explained your care and treatment options?	Yes, completely	341 (46.6)
	Yes, to some extent	299 (40.9)
	No	61 (8.3)
	I didn't need an explanation	23 (3.1)

Table 13 Provision of information (continued)

		IBD (n=731)
		n (%)
D1 Does your treating team provide an opportunity for your family/carer to be involved in education/information sharing?	Yes, completely	203 (27.8)
	Yes, to some extent	150 (20.5)
	No	197 (26.9)
	They didn't need to be involved	174 (23.8)
D1 Have you ever been given printed information about IBD?	Yes	527 (72.1)
	No	158 (21.6)
	Unsure	39 (5.3)
D1 Do you have an agreed plan with your treating team about what to do if your symptoms worsen, or you experience treatment side effects?	Yes	364 (49.8)
	No	270 (36.9)
	Unsure	90 (12.3)

Respondents with access to an IBD nurse more commonly had their care options explained (58.7%) than those without access (41.3%) (see Appendix 2).

The majority of participants received enough information when required from their specialist (88.8%) and their IBD nurse 79.4%, (**Table 14**).

Table 14 When you had IBD related questions to ask, did you get enough information from these providers?

	Specialist	GP	Dietitian	Pharmacist	IBD Nurse	ED Staff
n=724						
	n (%)					
Yes, completely	348 (48.7)	148 (20.5)	99 (28.5)	98 (15.4)	159 (48)	29 (8.7)
Yes, to some extent	301 (42.1)	315 (43.6)	140 (40.3)	212 (33.4)	104 (31.4)	129 (38.6)
No	55 (7.7)	142 (19.7)	81 (23.2)	66 (10.4)	23 (6.9)	120 (35.9)
I had no need to ask	11 (1.5)	117 (16.2)	27 (7.8)	259 (40.8)	45 (13.6)	56 (16.8)

D2 Education for patients & D3 Patient Support Groups

IBD educational forums were accessible to 35% of respondents and 56.1% took the opportunity to attend (**Table 15**). Advice on how to find patient support organisations was provided to only 35.7% of respondents. Online IBD support and information was accessed by 51%.

Table 15 Education and support groups

		IBD (n=731)
		n (%)
D2 Have you ever had access to attend an IBD educational forum?	Yes	260 (35.6)
	No	410 (56.1)
	Unsure	54 (7.4)
D2 If you had access to a forum, did you attend it?	Yes	149 (57.3)
D3 Has a health professional ever told you how to find a Crohn's or colitis patient support organisation?	Yes	261 (35.7)
	No	421 (57.6)
	Unsure	42 (5.7)
D3 Do you regularly access online IBD forums or websites for IBD information?	Yes	377 (51.6)
	No	325 (44.5)
	Unsure	22 (3)

Standard E: Data, information technology and audit

Services should use data, IT and audit to support patient care effectively and to optimise clinical management. The implementation standards focus on clinical registers, electronic patient management systems and audit of clinical care by clinicians. While these processes are likely to impact the patient experience, they are rarely visible to patients and accordingly were not surveyed through patient reported experience. Data on this standard is available through the IBD Audit 2016.

Standard F: Evidence-based practice and research

Patients should have access to participate in research trials though 78.4% were never offered the opportunity to receive treatment via a research trial (**Table 16**). However, 67.7% of those who had been offered trial participation accepted this offer.

Table 16 Research

		IBD (n=731)*
		n (%)
F2 Have you ever been offered the opportunity to receive treatment through a research trial?	Yes	124 (17)
	No	573 (78.4)
	Unsure	27 (3.7)
F2 If yes, did you participate in a research trial?	Yes	84 (67.7)

Opportunity to participate in research trials was greater in public IBD clinics (37.1%) compared with public outpatients (21.2%), private specialist patients (13.2%) and GP managed patients (3.1%), (see Appendix 1), and for those with access to an IBD nurse (30.2%) compared to those who didn't have access (10.9) (see Appendix 2).

6. Improving quality of care – patient perspective

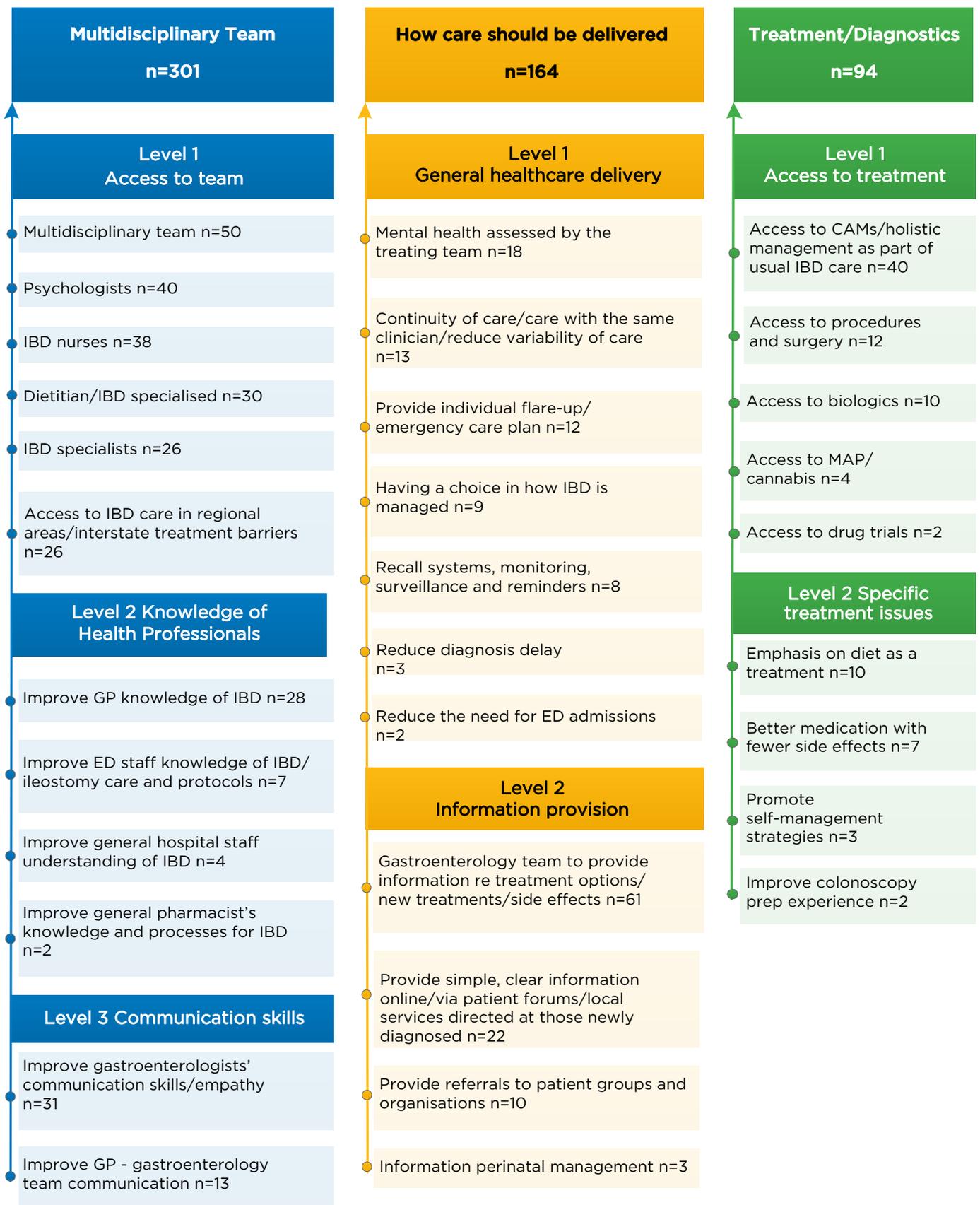
Participants were invited to respond to the question *What changes would you make to improve healthcare for your IBD?* Most participants responded, with 663 individual comments, which were coded and grouped into themes represented in **Figure 4**.

Overall 301 comments related to the multidisciplinary team. Respondents wanted more access to the team as a whole (n=50) and individual members of the team: psychologists (n=40), IBD nurses (n=38), dietitians (n=30), and IBD specialist physicians (n=26). Need for these services in rural/regional areas was reported (n=26). Respondents also wanted improved knowledge of IBD in GPs (n=28) and emergency department team members (n=7). Improvement in gastroenterologist communication and empathy to individual patients was suggested (n=31). There was also a need for better GP – team communication (n=13).

Improvements in the delivery of care (n=164) was the second most prevalent theme. Respondents wanted assessment of mental health (n=18), provision of flare up/emergency plans, recall/surveillance systems (n=8) and referral to patient support groups (n=10) as part of normal care. Greater continuity of gastroenterologist and other clinicians (n=13) and more choice in their management (n=9) would support patients' confidence in their care. The provision of information in simple clear language via multiple delivery platforms for newly diagnosed (n=22) was needed.

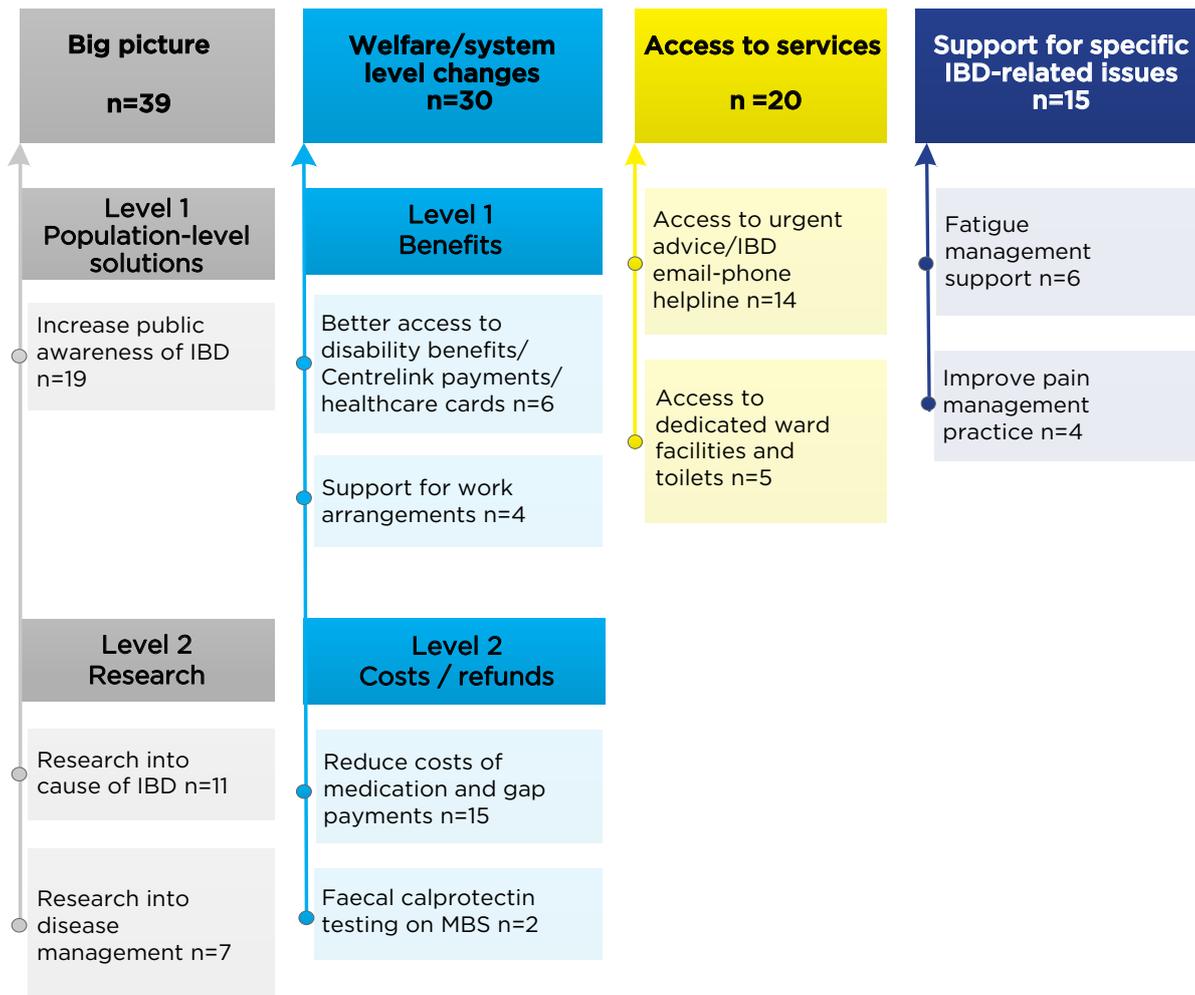
The treatment and diagnostic management theme (n=94) primarily focused on the will to have treatment managed as a whole, including complementary therapy (n=40). More specific access to procedures/surgery (n=12), biological therapies (n=10) and diet-related interventions (n=10) was required.

Other themes included access to services (n=20) including access to helplines for urgent advice; support for specific IBD-related issues (n=15) such as fatigue and pain, and welfare/system level changes (n=30) such as disability eligibility and medication costs. Broader population level changes (n=39) were also wanted including greater awareness of IBD in the general community and more research into the cause and disease management.



Single comments (n=1) are not shown but are included in theme totals

Figure 4 Changes to improve healthcare themes



Important findings

The response total of 1024 participants makes this the largest patient experience survey of people living with IBD in Australia and complements the scale of the IBD Audit undertaken by CCA 2016. The majority of participants in this study were currently experiencing illness as a result of their condition, had the condition long-term and were managed by a private specialist. For many the experience of care did not meet the level described in the Australian IBD Standards 2016, in particular, multidisciplinary care was lacking. Co-morbidity of mental health distress was common and mental health services were not readily accessed despite willingness to engage with them. Standards of care were also not met in various areas including multidisciplinary care, responsiveness, choice in care and clinical communication.

Burden of disease

Participants reported living with the condition for a mean of 14.2 years and at the time of survey most had active disease: Manitoba Index 69.6%, IBD-Control-8 63.2% PRO2 for ulcerative colitis 55.1% and PRO3 for Crohn's disease patients 57.4%. The variability between these tools was unexpected but is not the focus of this study. More than a quarter (26.8%) had been admitted overnight in the past year and of those, more than three quarters (77.6%) were unplanned or emergency admissions. This is higher than the IBD Audit emergency admission rate of 60%. Biologic therapies were used by 38.7% of participants, higher than the reported rates for the IBD Audit (16%-26%). Steroids were used for more than six weeks in the previous year by 39.9% of respondents, an indicator of poorly controlled disease.

The experience of care often did not include access to, or achieve the level of quality, set out in the Australian IBD Standards 2016.

Multidisciplinary care

Patients most commonly were managed by a private specialist (57%). Less commonly respondents were managed by public IBD specific outpatient clinic (19%). While almost all respondents had access to a gastroenterologist in their treating team, only a third had access to IBD nurses (32.4%), dietitian (30.9%) or pharmacist (26.1%). Even fewer (12%) had a psychologist in their team, reflecting low levels of access described in the IBD Audit (4% of sites had a

psychologist as a member of the team). This multidisciplinary team access falls short of the standard. Perhaps more importantly, the gap in services is identified as the most common need by respondents in the qualitative data, where they request multidisciplinary care, psychologists, IBD nurses and dietitians respectively. Another of the qualitative themes concerned the need for more information provision by the IBD team, a task well suited to the multidisciplinary team enabling patients to better self-manage their own condition.

Mental health

Psychological distress was common (with nearly 50% reporting some level of distress). Overall, 15.2% of the respondents reported seeing a mental health practitioner and for the majority of those respondents this was a psychologist. Only 16.1% of respondents were asked about their mental health by their specialist or IBD Nurse and 56% of those not asked would have liked to be asked.

Those distressed reported lower satisfaction with IBD care (63% vs 85%). The large majority of them had active IBD (84%). Those distressed had a nearly double rate of fistulas, perianal disease, and current steroid use. They were almost three times more likely to take opioids and psychotropics than those without distress.

Those distressed more commonly reported having been hospitalised for their IBD in the last 12 months (31% vs 22%), more commonly reported pain (63% vs 26%) or fatigue (84% vs 42%). Those distressed would have liked to be asked about their mental health by their gastroenterology team (74% vs 40%), less commonly had a plan of their IBD being reviewed annually (78% vs 86%) or reported that their care was explained to them (38% vs 55%).

The IBD Audit identified that mental health condition was the most common comorbid condition affecting more than a quarter of hospitalized patients. It also identified that less than a quarter of these patients received psychological support, and only one third of those with severe distress received mental health support. Mental health conditions and distress are prevalent in the IBD community but there is a lack of active identification of these issues for individuals, despite the willingness of participants to discuss mental health, and the association with pain, fatigue and opioid use.

Responsive care

There were gaps in service for people who experienced deterioration in their condition. It is a standard that specialist advice is available to those with a possible relapse within 5 days. When experiencing a relapse, a third (30.8%) of respondents had to wait more than 14 days to see a specialist. Only half (49.8%) had a plan of what to do if their condition deteriorated. If in doubt, the availability of IBD helplines was limited to just over half (55.4%) of respondents which is consistent with the IBD Audit which reported availability of helplines in half (51%) of sites.

Choice and clinician communication

Most participants had their care treatment explained but the quality of the information and their involvement in decision making varied. Medical specialists (48.7%) and IBD nurses (48%) most commonly provided the most complete advice for patients IBD questions. Nearly two-thirds of patients (63.1%) had a choice in their treatments which is consistent with the IBD Audit where 64% of sites said they actively encouraged involvement in care decisions. However, 51% of respondents in this survey wanted to be more involved in decisions about their treatment. Concern about lack of involvement in treatment was reflected in qualitative themes such as more choice in care and better, more empathic, specialist communication.

Despite the variability in experience of care, overall the majority of respondents (74.8%) responded that they were satisfied with the IBD healthcare they received. Generally, patient satisfaction questions ask patients to give subjective responses and are influenced by expectations rather than fact whereas patient experience is concerned with what did or did not occur during health care^{xvi xvii}. This data highlights the need to improve awareness of quality of care to raise the expectations of care so that individuals don't accept as normal: active disease, distress, unresponsive healthcare provision and lack of choice and involvement.

Service environments

Some standards of care had significantly different results depending on what the recent, predominant outpatient management setting was (public outpatient clinic, public IBD clinic, private specialist or GP) or whether the participant had access to an IBD nurse or not.

There was better access to members of the multidisciplinary team for participants managed by public IBD clinics. In particular they were more likely to have access to an IBD nurse (83.7%) than the next most likely - public outpatient clinic (54.5%). They were more likely to have access to a helpline (80.7%) than next most likely - public outpatient clinic (59.1%). They were also more likely to have an opportunity to participate in research trials (37%) than next most likely - public outpatient clinics (21%). While none of the service environments have met the standard for multidisciplinary care, IBD nursing or helpline, there is significant variability in access for participants associated with service environment.

Those managed by private specialists (84%) were more confident that their GP is kept informed about their treatment/results than other settings (all below 67%).

Those with access to an IBD nurse (77.1%) are more likely to have access to a helpline than those that do not (45.2%) This is consistent, though not as marked, with the IBD Audit 92% vs 29%. Respondents with access to an IBD nurse more commonly had their care options explained (58.7%) than those without access (41.3%) and were more clear on what issues they should seek specialist/hospital and GP care for (82.4% vs 69.5%).



Limitations of this study

There are a number of limitations associated with this online, adult, patient reported survey:

- Only those aged 16 or more were eligible to participate. There is a need to specifically survey the patient experience of children, adolescents and their parents on the experience of IBD care.
- Severity of disease was classified according to validated patient expressed measures but lacked objective measures because all data was collect through patients.
- There was low participation from people in remote areas.
- The female participation rate is high in this survey.
- Online data collection can exclude potential participants who do not access online surveys

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Appendix 1 Comparison of management setting for various IBD Standards

	Total	Public outpatient clinic	Public IBD outpatient clinic	Private specialist	GP
	n=731	n=66	n=141	n=420	n=66
A1 The IBD Team	707 (96.7)	64 (9.7)	137 (97.2)***	414 (98.6)	60 (90.9)
Gastroenterologist	237 (32.5)	36 (54.5)	118 (83.7)***	69 (16.5)	9 (13.6)
IBD Nurse	88 (12)	6 (9.1)	24 (17)	46 (11)	8 (12.1)
Psychologist	226 (30.9)	23 (34.8)	69 (48.9)***	107 (25.5)	14 (21.2)
Dietitian	75 (10.3)	10 (15.2)	29 (20.6)***	31 (7.4)	1 (1.5)
Stoma Nurse	192 (26.3)	22 (33.3)	42 (29.8)	106 (25.2)	16 (24.2)
Colorectal surgeon	191 (26.1)	15 (22.7)	39 (27.7)	105 (25)	21 (31.8)
Pharmacist	599 (81.9)	26 (39.4)	60 (42.6)	376 (89.5)***	49 (74.2)
A7 Have you ever chosen to have a colonoscopy or surgical treatment for your IBD through the private system?	Yes				
B1 Is your GP involved in your IBD care?	Yes	44 (66.7)	98 (70)	280 (66.7)	58 (87.9)**
B1 Do you think your GP is kept informed about your results and treatment by your specialist/hospital?	Yes	42 (63.6)	94 (67.1)	352 (84)***	44 (67.7)
C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	Yes	39 (59.1)	113 (80.7)***	229 (54.5)	18 (27.3)
C3 Do you use any complementary therapies?	Yes	16 (24.2)	35 (25)	150 (35.9)**	18 (28.1)
C3 Does your doctor ask what complementary therapies you use, if any?	Yes	13 (19.7)	45 (32.1)	141 (33.7)*	17 (26.6)
C4 Have you been given a choice on how you participate in follow up care, e.g. specialist rooms, outpatient clinic or GP shared care?	Yes	15 (22.7)	41 (29.3)	103 (24.6)	14 (21.9)
	No, but I would like a choice	18 (27.3)	29 (20.7)	69 (16.5)	20 (31.3)***
C5 Have you ever been asked for feedback about your IBD care such as a survey, feedback card, web form, open day?	Yes	18 (27.3)	47 (33.6)***	56 (13.4)	6 (9.4)
D1 Do you have an agreed plan with your treating team about what to do if your symptoms worsen, or you experience treatment side effects?	Yes	35 (53)	81 (57.9)**	216 (51.8)	23 (35.9)
D1 Has a member of your treatment team explained completely your care and treatment options?	Yes	33 (50)	76 (54.3)***	212 (50.8)	15 (23.4)
D1 Does your treating team provide an opportunity for your family/carer to be involved in education/information sharing?	Yes, completely	18 (27.3)	45 (32.1)*	126 (30.2)	11 (17.2)
	Yes, to some extent	15 (22.7)	27 (19.3)	85 (20.4)	14 (21.9)
D1 When you had IBD related questions to ask your specialist doctor, did you get enough information?	Yes	30 (45.5)	74 (52.9)	223 (53.5)***	14 (21.9)
D1 Were the short and long-term side effects of steroids explained to you at any point in time?	Yes	19 (28.8)	47 (33.6)	153 (36.7)**	14 (21.9)
D2 Have you ever had access to attend an IBD educational forum?	Yes	17 (25.8)	47 (33.6)	164 (39.3)*	22 (34.4)
F2 Have you ever been offered the opportunity to receive treatment through a research trial?	Yes	14 (21.2)	52 (37.1)***	55 (13.2)	2 (3.1)

* p<0.05, **p<0.01, ***p<0.001

Appendix 2 Comparison of IBD nurse access for various IBD Standards

	Total	IBD Nurse access	No IBD Nurse access
	n=731	n=237	
A11 Is there a plan for your IBD to be reviewed at least once per year even if you are well?	598 (82.3)	215 (91.1)***	383 (78)
B1 If your GP is involved in your IBD care, are you clear on what issues you should seek specialist/hospital care for?	373 (73.7)	136 (82.4)**	237 (69.5)
B1 Do you think your GP is kept informed about your results and treatment by your specialist/hospital?	554 (76.4)	175 (74.2)*	379 (77.5)
C2 Does your treating team provide access to an email or telephone help line where you get a response by the end of the next day?	404 (55.6)	182 (77.1)***	222 (45.2)
C3 Do you have a choice in what treatment you have?	460 (63.6)	166 (70.6)*	294 (60.2)
C3 Do you use any complementary therapies?	239 (33.1)	61 (26)*	178 (36.5)
C4 Have you been given a choice on how you participate in follow up care, e.g. specialist rooms, outpatient clinic or GP shared care?	176 (24.3)	67 (28.5)*	109 (22.3)
C5 Have you ever been asked for feedback about your IBD care such as a survey, feedback card, web form, open day?	147 (20.3)	47 (20)	100 (20.5)
D1 Has a member of your treatment team explained <u>completely</u> your care and treatment options?	129 (17.8)	76 (32.3)***	53 (10.9)
D1 Does your treating team provide an opportunity for your family/carer to be involved in education/information sharing?	339 (47)	138 (58.7)***	201 (41.3)
D1 Have you ever been given printed information about IBD?	202 (28)	85 (36.2)**	117 (24)
D1 When you had IBD related questions to ask your specialist doctor, did you get enough information?	150 (20.8)	48 (20.4)	102 (20.9)
D2 Have you ever had access to attend an IBD educational forum?	526 (72.9)	189 (80.4)**	337 (69.2)
D3 Has a health professional ever told you how to find a Crohn's or colitis patient support organisation?	348 (48.1)	127 (54)**	220 (45.2)
F2 Have you ever been offered the opportunity to receive treatment through a research trial?	260 (36)	94 (40)**	166 (34.1)
	261 (36.1)	100 (42.6)*	161 (33.1)
	124 (17.2)	71 (30.2)***	53 (10.9)

* p<0.05, **p<0.01, ***p<0.001

Appendix 3 Supplementary inpatient data

		IBD (n=196)
		n (%)
D1:	When you had important questions to ask a doctor, did you get answers that you could understand?	
	Yes, always	89 (45.4)
	Yes, sometimes	77 (39.3)
	No	21 (10.7)
	I had no need to ask	9 (4.6)
D1	When you had important questions to ask a nurse, did you get answers that you could understand?	
	Yes, always	81 (41.3)
	Yes, sometimes	77 (39.3)
	No	27 (13.8)
	I had no need to ask	11 (5.6)
D1	If you have had IBD related surgery, did you get adequate information before the operation?	
	Yes	70 (35.7)
D1	Did the doctors or nurses give your family or someone close to you all the information they needed to help you recover?	
	Yes, definitely	51 (26)
	Yes, to some extent	42 (21.4)
	No	76 (38.8)
	No family or friends were involved/My family or friends didn't want or need information	27 (13.8)
D1	Did someone tell you about danger signals regarding your illness or treatment to watch for after you went home?	
	Yes, completely	60 (30.6)
	Yes, to some extent	66 (33.7)
	No	70 (35.7)
A13	Did the hospital care team asked about any mental health concerns (even if not related to your IBD)?	
	Yes	36 (18.4)
A13	Did you access mental health support while in hospital?	
	Yes, with a psychologist	5 (0.7)
	Yes, with a psychiatrist	4 (0.5)
	Yes, with a counsellor	2 (0.3)
	Yes, with a social worker	6 (0.8)



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