



Inflammatory Bowel Disease Paediatric Quality of Care

Patient Experience Survey 2023

Research Report



About CCA

Crohn's & Colitis Australia's primary purpose is to provide support services, advice and encouragement to people with inflammatory bowel disease (IBD). Whilst CCA doesn't cure the illness it can remove some of the burden for people living with IBD and their families.

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.

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

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Executive Summary

Inflammatory bowel disease (IBD) is estimated to affect over 100,000 people in Australia and is increasing locally and globally. Crohn's disease and ulcerative colitis, the most common IBDs are chronic, lifelong gastrointestinal disorders with unpredictable, and often debilitating symptoms. Up to 25% of IBD is diagnosed in childhood and adolescence, potentially affecting growth, puberty, education and psychosocial development. Hospital costs, productivity losses and indirect expenses of IBD management to the Australian public were estimated at \$2.7 billion in 2013.

In Australia IBD quality of care has been shown to be variable for young people and fall short of the national standards. The Australian Government's IBD National Action Plan identifies as a priority the need to for increased investment in research and focus on children with IBD.

Crohn's & Colitis Australia with assistance from the Gastroenterological Society of Australia undertook a two-year project to:

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

This IBD Paediatric Patient Experience survey was conducted through national online survey of parents/carers and teenagers. This data is complemented by direct patient feedback from young people (under 18) collected through family interviews.

Surveys from 266 respondents and 35 family interviews resulted in the following findings.

Youth living with IBD are confronted with a high disease burden

- Disease burden substantial well before diagnosis.
- Long delays, uncertainty, repeated or invalidating experiences with health professionals, and the emotional strain of coping with the youth's physical deterioration often reported.
- Reports of active disease (Manitoba Index: 66.9%) and reliance on escalated biologic therapies (>6 weeks: 54.9%) common.
- More than one in three youth (35.1%) hospitalised in the past year, largely through unplanned or emergency admissions (76.3%).
- Diagnostic and treatment procedures recounted as unfamiliar "first-time" events marked by apprehension, and in some instances, profound distress or trauma.

IBD can impose a profound psychological burden on young people

- IBD's emergence a pivotal event for youth, imposing a reorganisation of 'normal' life, and for some, difficult psychological adjustment.
- The risk of mood or anxiety disorder among youth in this research substantial (50.8%) and often co-occurred with symptomatic disease.
- High psychological burden associated with greater self-report active IBD (Manitoba Index: 75.4% vs. 57.7%), past-year overnight inpatient care (44.4% vs. 31.7%), opiate pain medication use (>6 weeks: 8.0% vs. 0.8%), and lower use of biologic therapies (current use - 16/17-year-olds: 45.8% vs. 80.0%).
- Access to mental health support identified as problematic. Over half reported no query about the youth's mental health from any health professional in the past year (62.4%); and less than a third that accessed mental health support felt it was easy to do so (29.7%). Accessible mental health support - the most common open-text suggestion for improved IBD care.

Families want care that extends beyond their primary specialist

- Despite the high psychological burden of youth, three-quarters (75.0%) reported no available psychologist in the youth's treating team.
- Urgent need for better access to and clarity of dietary advice; dietitians were available in the treating team and during hospital inpatient stays less than half the time (47.3% and 49.5%).
- Just over half reported access to a specialist IBD nurse in their treating team (52.3%) and being seen by one in inpatient care (51.5%).
- General practitioners involved in IBD care in only around half of cases (53.6%); respondents often not confident that their GP was informed of IBD care.

Care that is not tailored to the needs of young people

- More than a third of young people (38.3%) not referred to a paediatric gastroenterologist upon first suspicion of IBD.
- Information and educational opportunities more often afforded to and oriented to adults than youth.

Important information about managing IBD is often provided, but opportunities for education in key areas remain.

- Explanations of care and treatment options reported by almost all respondents (95.8%), but education fell short in other areas.
- A plan with the treating team in case of deterioration often absent or uncertain (42.9%) and more than one in seven reported no explanation of short- and long-term steroid side effects.

Access to prompt advice, specialist review, and procedures

- Waiting times for specialist review of a suspected disease relapse surpassed the national standard of five days for around half of respondents (49.8%), often exceeding two weeks (26.8%).
- Private system radiology and colonoscopy/surgery services often sought to avoid treatment delay (85.1% and 79.3%)
- Uncertainty or an outright lack of access to prompt advice via an email or phone helpline was common (23.7%). Accessibility of nurses and other health professional out-of-consultation advice paramount.

Next Steps

The quality of care for young people living with IBD will be further investigated through a Hospital Audit of the resources and organisation of care and clinical audit. Findings from this report and the Hospital Audit will be drawn upon to make recommendations for the improvement of quality of care for young people with IBD in Australia.

Background

Inflammatory bowel disease (IBD) is estimated to affect 100,000 people in Australia, with evidence that its prevalence is increasing locally and globally.¹ Hospital costs, productivity losses and indirect expenses of IBD management to the Australian public are estimated to exceed \$2.7 billion annually.² The disease is characterised by chronic, unpredictable, and often debilitating symptoms, including abdominal pain, bloody diarrhoea, frequent bowel movements (i.e., 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. Up to 25% of IBD will be diagnosed in childhood and adolescence,³ potentially affecting growth, puberty, education and psychosocial development.^{2,3,4}

The increased incidence and prevalence of IBD in young people⁵ 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. 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 short of the national standards.⁶ 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.⁷ Understanding care experiences from the paediatric patient perspective is required to understand the quality of healthcare in IBD. Patient-centred care⁸ and consumer co-creation in health⁹ have been shown to improve the safety and quality of health care. This is reinforced by the Australian Government's IBD National Action Plan,¹⁰ 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.

Crohn's & Colitis Australia is undertaking a 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 the subject of this report. This exploratory study is based on the general survey design of the 2018 CCA Patient Experience Survey. It uses adapted survey tools for parents, guardians and carers of people under 18. In addition, patient experience information from young people (under 18) is collected through family interviews.

Methodology

This research used a cross-sectional mixed-methods approach to address the dual aims of 1.) Measuring and comparing paediatric IBD care against the National Standards,⁴ and 2.) Gaining an in-depth and person-centred understanding of how this care is experienced first-hand by its recipients.

Survey tool

Anonymous quantitative data were collected via the web-based questionnaires tailored to parent/carer and 16/17-year-old respondents using the Qualtrics⁵ survey platform. Questionnaires comprised items based on the Australian IBD Standards 2016⁴ and adapted from CCA's 2018 Patient Experience Survey.⁶ Disease activity indices included the Manitoba Index,⁷ the PRO2⁸ for ulcerative colitis and the PRO3⁹ for Crohn's disease. The Kessler Psychological Distress Scale (K10)¹⁰ and Paediatric Symptom Checklist-17 (PSC-17)¹¹ were used to measure youth psychological burden via 16/17-year-old and parents/carer respondents respectively. High and low psychological burden groups were defined by established guidelines and cutoffs suggestive of an increased risk of mood and anxiety disorder.¹²⁻¹⁴ Experiences regarding interactions with health professionals in the hospital inpatient setting were assessed via several items from the Picker Patient Experience-15 questionnaire (PPE-15).¹⁵ The questionnaires were revised iteratively based on feedback from an advisory group of consumers, researchers and clinicians to verify its functional usability and consistency with the research aims.

Family interviews

Participants elected to participate in the family interviews which sought to gather data directly from all ages under 18 years upon completing the online questionnaire. A research team member contacted those who expressed their interest to attend an interview via video conference and obtained informed verbal consent prior commencement. Interviews involved the youth with IBD, their parent/s or carer/s and, where feasible, their siblings. Interviews began with 'icebreaker' activities to establish rapport with families and a comfortable space for youth to participate in candid conversations about their experiences.

Questions encompassed the family social sphere and those involved in the youth's IBD care, the youth's knowledge, sources, and strategies regarding IBD information, and their perceptions and emotional experiences related to doctor/clinic visits, their specialist doctor, IBD-related procedures (e.g., colonoscopy), and treatment environments (e.g., waiting rooms, hospitals).

Eligibility

To be eligible for inclusion, participants had to be a parent/carer of a young person (< 18 years) diagnosed with Crohn's disease, ulcerative colitis, or indeterminate colitis, or a young person (16-17 years) living with Crohn's disease, ulcerative colitis, or indeterminate colitis or a young person aged 15 and under (family interview only). Respondents had to be able to respond to an English-language questionnaire and an Australian resident or citizen receiving healthcare in the country.

Recruitment

Participants were recruited through a combined strategy involving:

- CCA advertising via email, web, social media, member communication channels, associated IBD networks, and dissemination by project committee members.
- Email and hardcopy mail-out invitations sent to private and public hospital-attending youth and their parents/carers.

Procedure and data collection period

Invitations directed respondents to a Plain Language Statement outlining the study's purpose, anticipated benefits and risks, eligibility requirements, data collection procedure, and privacy and confidentiality information. Respondents were informed that continuing with the questionnaire would be accepted as implied consent for their inclusion. Those who proceeded with the questionnaire could save and complete their response in multiple sittings if required until the survey close date. Survey data were collected from 3 March to 30 July 2022, and family interviews were conducted between 26 May and 18 August 2022.

Statistical analysis

The web-based quantitative survey dataset was cleaned and analysed using SPSS, R, Jamovi, and Microsoft Excel. Data were subject to descriptive analyses evaluating frequencies (%), central tendency and dispersion (i.e., mean [SD], median [IQR]). Between-group comparisons were assessed with one-way ANOVA and Student's t-test for continuous outcomes. Group comparisons across categorical outcomes were assessed with the chi-square test of independence and Fisher's exact test in cases where expected cell sizes were small (i.e., >20% with five or fewer cases).

Anonymised interview recordings were transcribed and imported into NVivo 12 Plus¹⁶ software for organisation and coding. Data were assessed using an inductive template thematic analysis,¹⁷ whereby preliminary familiarisation and analyses of a data subset inform the development of a coding template used in, and iteratively revised by, the coding of remaining data. This strategy provides methodological structure to guide specific research questions while ensuring comprehensiveness through flexible template modification to include all data pertinent to the study's scope.^{17,18}

A preliminary template was developed by coding approximately 30% of transcribed data and subsequently refined through review and coding of the remaining text.

Governance and ethics

The Patient Experience Survey is led by Crohn's & Colitis Australia and funded by the Australian Government Department of Health. The project is overseen by a multidisciplinary Project Advisory Committee comprised of important stakeholders in IBD health care, including consumers (see Acknowledgements for membership). The committee is chaired by Dr Ed Giles, a member of CCA's Scientific, Medical and Quality of Care Advisory Committee, which reports to the CCA board. Ethics approval was obtained from the Monash Human Research Ethics Committee (HREC: RES-21-0000755L).

Survey Findings

Sample

The online survey was accessed by 297 respondents, of whom 266 (89.6%) progressed past the threshold for case inclusion (i.e., completion of demographic questions or beyond). In total, 243 of the 297 respondents accessing the survey completed it in its entirety (completion rate = 81.8%).

Demographics

Survey responses comprised demographic data for 266 youth with IBD described by themselves (16-17 years) or their parent/carer (0-16 years) (Table 1). There was a near-even split of male and female youth (49.6% female vs. 50.4% male), with most living in either a major Australian city or an inner regional area (91.6%). The majority spoke English as their main language at home (94.7%), and around one-quarter (27.8%) indicated a current CCA membership. Data from 16/17-year-old respondents showed that most were living with two parents (73.3%), students (77.8%), and relatively few were employed casually/part-time (15.6%) or fulltime (4.4%). The demographic characteristics of parent and carer respondents are shown in Appendix 1 (n = 221). The large majority were female (94.1%) and in a married or de facto relationship (89.6%). Approximately half had a university-level education (50.3%), and most were employed part- or full-time (75.1%).

Participants from each state and Australian Capital Territory were represented in the data (Figure 1).

Table 1 Youth demographic characteristics

N = 266		n (%)
Age - Mean (SD), range (years)	14.3 (3.2), 0-17	
Gender		
Female		132 (49.6)
Male		134 (50.4)
Remoteness		
Major city		192 (72.7)
Inner regional		50 (18.9)
Outer regional		20 (7.6)
Remote		0 (0.0)
Very remote		2 (0.8)
Main language at home		
English		252 (94.7)
Other (please specify)		14 (5.3)
CCA membership		
Yes		74 (27.8)
No		192 (72.2)
Number of parents living with[#]		
1 parent		11 (24.4)
2 parents		33 (73.3)
Other (please specify)		1 (2.2)

Employment status[#]		n (%)
Employed full time		2 (4.4)
Employed casual or part time		7 (15.6)
Student		35 (77.8)
Other (please specify)		1 (2.2)

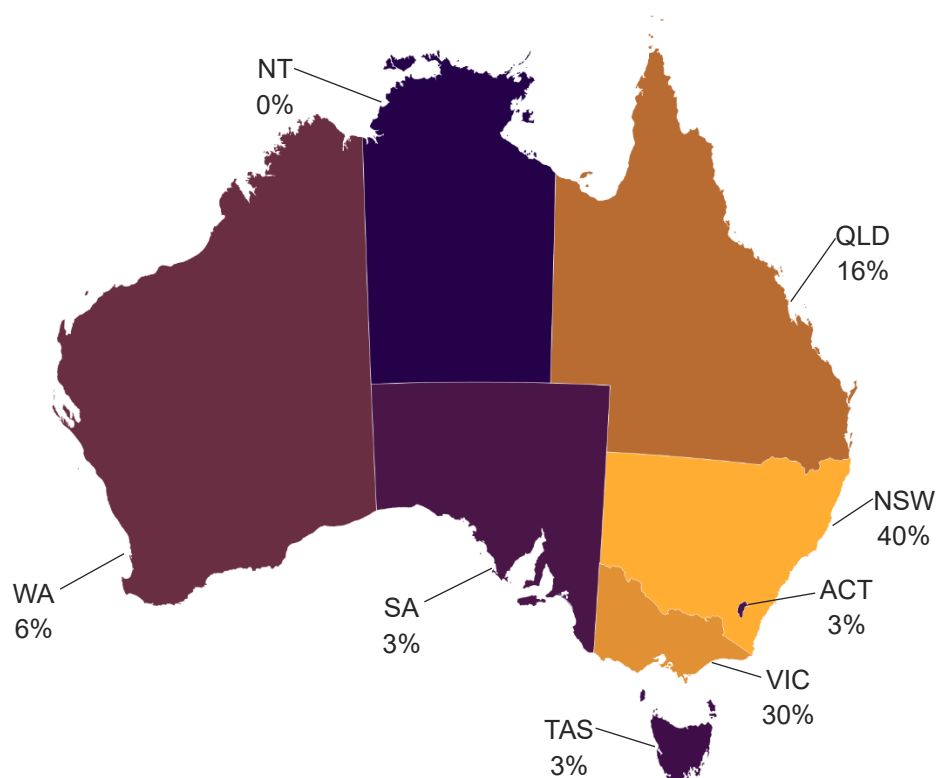


Figure 1 Survey respondents by state and territory

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Clinical characteristics

The youth had been diagnosed with IBD for an average of 3.5 years (Table 2), with Crohn's disease being the most common diagnosis (56.8%). Self-reported disease activity suggested an active IBD state in approximately two-thirds of youth via the Manitoba Index⁷ (66.9%). Subtype-specific disease activity measures were more conservative, suggesting active disease in 41.2% of youth with Crohn's disease (PRO3)⁹ and 48.9% of those with ulcerative colitis (PRO2).⁸

Table 2 Clinical characteristics

	n (%)
Diagnosis	
Crohn's disease	151 (56.8)
Ulcerative colitis	96 (36.1)
IBD unclassified	19 (7.1)
Years diagnosed - Mean (SD), range (years)	3.5 (3.1), 0-17
Manitoba index	
Constantly active, giving me symptoms every day	41 (16.3)
Often active, giving me symptoms most days	40 (15.9)
Sometimes active, giving me symptoms on some days (for instance 1 – 2 days per week)	58 (23.1)
Occasionally active, giving me symptoms 1 – 2 days per month	29 (11.6)
Rarely active, giving me symptoms on a few days in the past 6 months	38 (15.1)
I was well in the past 6 months, an improvement or absence of symptoms.	45 (17.9)

Manitoba Index - active/inactive	
Inactive	83 (33.1)
Active	168 (66.9)
PRO3 - Crohn's disease only (n = 141)	
Clinical remission	83 (58.9)
Mildly active disease	30 (21.3)
Moderately active disease	28 (19.9)
Severely active disease	0 (0.0)
PRO2 - ulcerative colitis only (n = 90)	
Inactive	46 (51.1)
Active	44 (48.9)

Clinical environment and satisfaction with care

Most youth (73.9%) had their IBD primarily managed in the previous year through a public outpatient or public IBD-specific outpatient clinic (Table 3), and for most of the remainder, via a private specialist (17.8%). Most were managed in a paediatric clinic (85.5%), with the remainder largely managed in either an adult gastroenterology or IBD clinic (53.3%) and combination or unspecified/unclear care arrangements (36.7%).

Table 3 Clinical environment

	n (%)
Primary past-year IBD manager	
Public outpatient clinic	195 (73.9)
Private specialist	47 (17.8)
Other (please specify)	15 (5.7)
GP	4 (1.5)
IBD managed in a paediatric clinic	
Yes	224 (85.5)
No	28 (10.7)
Unsure	10 (3.8)
Non-paediatric management clinic	
Adult gastroenterology clinic or adult IBD clinic	16 (53.3)
Specific transition young adult clinic	3 (10.0)
Other	11 (36.7)

Participants were prompted with a single-item prompt regarding their overall satisfaction with their IBD healthcare. In the total sample, 81.4% indicated they were satisfied or very satisfied with their care. Both parent/carer and 16/17-year-old respondents' independent satisfaction ratings followed a similar distribution (Figure 2).

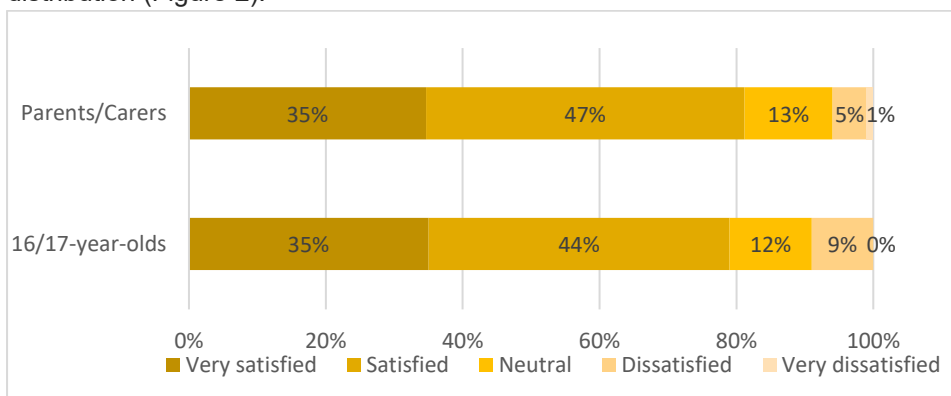


Figure 2 Overall satisfaction with IBD healthcare

Standard A: High-quality clinical care

A1: The IBD team & A2: Essential supporting services

Most respondents indicated an available paediatric gastroenterologist in their treating team (89.0%) and around half an IBD specialist nurse (52.3%) or dietitian (47.3%, Figure 3). Psychologists and pharmacists were reported with similar frequency (25.0% and 24.2%, respectively), closely followed by non-paediatric gastroenterologists (20.5%). Few indicated an available colorectal surgeon (7.1%) or stomal therapy nurse (6.1%).

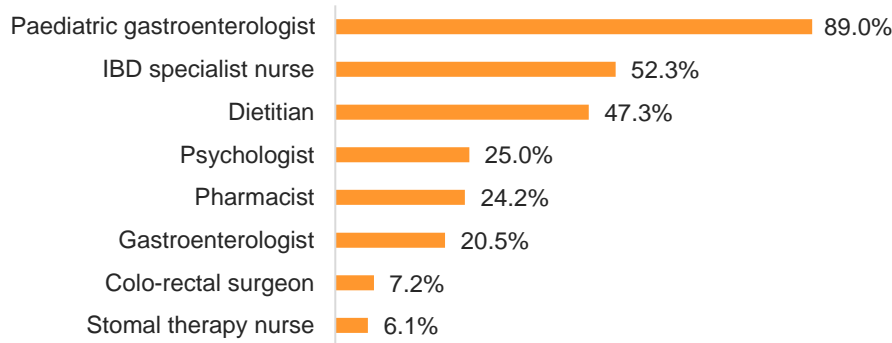


Figure 3 Specialists available in the youth's IBD treatment team

Selected medication use was surveyed in relation to IBD team prescribers (Table 4). The most common medications used for over six weeks in the previous 12 months were immunomodulators (75.0%), biologics (54.9%), and steroids (40.9%). Less commonly reported were dietary therapies (19.3%), mental health medications (9.5%), and opiates (4.2%).

Table 4 Use and prescribers of medication and dietary therapy in the previous 12 months

	n (%)	Prescriber	n (%)
Steroids			
Yes, I am currently taking them	26 (9.8)	Gastroenterologist	104 (96.3)
Yes, but I am no longer taking them	82 (31.1)	GP	3 (2.8)
No	152 (57.6)	Other (Please enter)	1 (0.9)
Unsure	4 (1.5)		
Immunomodulators			
Yes, I am currently taking them	185 (70.1)	Gastroenterologist	195 (99.0)
Yes, but I am no longer taking them	12 (4.5)	Other (Please enter)	2 (1.0)
Yes#	1 (0.4)		
No	59 (22.3)		
Unsure	7 (2.7)		
Biologics			
Yes, I am currently taking them	142 (53.8)	Gastroenterologist	143 (100.0)
Yes, but I am no longer taking them	2 (0.8)		
Yes#	1 (0.4)		
No	112 (42.4)		
Unsure	7 (2.7)		
Opiates			
Yes, I am currently taking them	6 (2.3)	Gastroenterologist	4 (40.0)
Yes, but I am no longer taking them	5 (1.9)	GP	4 (40.0)
No	250 (94.7)	Other (Please enter)	2 (20.0)

Unsure	3 (1.1)		
Mental health medications			
Yes, I am currently taking them	23 (8.7)	Gastroenterologist	1 (4.2)
Yes, but I am no longer taking them	2 (0.8)	GP	12 (50.0)
No	237 (89.8)	Other (Please enter)	11 (45.8)
Unsure	2 (0.8)		
Dietary therapies			
Yes, I am currently taking them	19 (7.2)	Gastroenterologist	47 (94.0)
Yes, but I am no longer taking them	32 (12.1)	GP	1 (2.0)
No	210 (79.5)	Other (Please enter)	2 (4.0)
Unsure	3 (1.1)		
#n = 1 did not provide a response for current use of the medication.			

A5: Access to nutritional support and therapy

Slightly fewer than half of respondents (47.3%, Figure 5) reported an available dietitian in their treating team, and a similar proportion (49.5%) reported the youth being seen by one during their inpatient hospital stay (Table 5, see *A8 & A10: Inpatient facilities & care*). Dietary therapies were used by 19.3% of youth overall and were comparatively more common among respondents who reported the availability of a dietitian in their treatment team (30.4% vs. 9.6%, $p < .001$).

A6: Arrangements for the use of biological and immunomodulator medicines

Over half the youth (55.0%) had taken biologic medication for more than six weeks in the previous year, all of whom had their treatment prescribed by a gastroenterologist (Table 4). In this group, nearly all youth continued to receive biologic therapy (98.6%). Immunomodulators were prescribed by a gastroenterologist in all but two cases and were used for more than six weeks in the previous year by three-quarters of youth (75.0%). Most of this group (93.9%) continued to take immunomodulator medication.

A8 & A10: Inpatient facilities & care

Over a third of youth (35.1%) had been in overnight hospital inpatient care in the last year (Figure 4), approximately three-quarters of which reported an emergency or unplanned admission (76.3%). Most respondents indicated that toilet facilities were adequate for the youth's needs and privacy (81.4%, Table 5), and around half had been seen by an IBD specialist nurse (51.5%) or dietitian (49.5%). Most reported feeling that the youth had been treated with respect and dignity during their stay (97.9%).

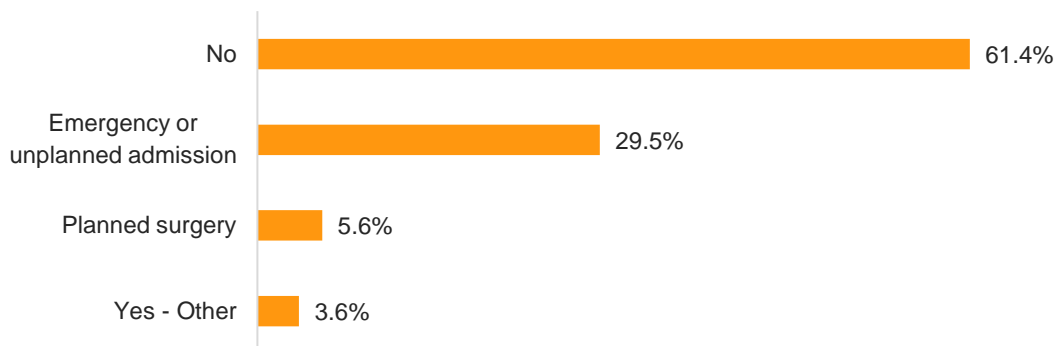


Figure 4 Frequency of overnight youth inpatient hospital care in the last year

Table 5 Inpatient facilities and care

	n (%)
Was your/their bed situated in a:	
Paediatric gastroenterology ward	62 (63.9)
Other (please specify)	25 (25.8)
Unsure	9 (9.3)
Adult gastroenterology ward	1 (1.0)
The ward you/they were in mainly had patients who were:	
Children of all ages	79 (81.4)
Adolescents	14 (14.4)
Adults	4 (4.1)
During your/their most recent hospital stay due to IBD: Were the toilet facilities adequate for their needs and privacy?	
Yes	79 (81.4)
No	17 (17.5)
N/A	1 (1.0)
Were you/they seen by a dietitian?	
Yes	48 (49.5)
No	45 (46.4)
Not sure	4 (4.1)
Were you/they seen by an IBD specialist nurse?	
Yes	50 (51.5)
No	43 (44.3)
Not sure	4 (4.1)
Overall, did you feel you (the youth)/they were treated with respect and dignity while they were in hospital?	
Yes, always	74 (76.3)
Yes, sometimes	21 (21.6)
No	2 (2.1)
#16/17-year-old respondents only	
##Parent/carer respondents only	

A9: Access to diagnostic services

Respondents commonly sought care via the private system for colonoscopy or surgical treatment (42.4%) and, to a lesser extent, for radiology services (28.2%, Table 6). Most of those seeking private colonoscopy/surgery and radiology services opted to do so for earlier treatment (79.3% and 85.1%, respectively).

Table 6 Diagnostic service access

	n (%)
Have you ever chosen to have a colonoscopy or surgical treatment for your IBD through the private system?	
Yes	111 (42.4)
No	142 (54.2)
Unsure	9 (3.4)
If yes, was it because you could receive treatment sooner?	
Yes	88 (79.3)
No	17 (15.3)
Unsure	6 (5.4)

Have you ever chosen to have radiology (e.g. MRI) for your IBD through the private system?	
Yes	74 (28.2)
No	179 (68.3)
Unsure	9 (3.4)
If yes, was it because you could receive treatment sooner?	
Yes	63 (85.1)
No	8 (10.8)
Unsure	3 (4.1)

A11: Outpatient care

Most respondents reported a plan for an annual review of the youth's IBD (79.3%) and an email or phone contact point with a prompt, end-of-next-day response (76.2%, Table 7). Nevertheless, the wait for a specialist review of disease relapse was highly variable. While more than a quarter reported a one to two-day wait (28.7%), a similar proportion waited for one to two weeks (23.0%) and more than a fortnight (26.8%).

Table 7 Outpatient care

	n (%)
Is there a plan for the youth's IBD to be reviewed at least once per year even if they are well?	
Yes	207 (79.3)
No	19 (7.3)
Unsure	35 (13.4)
Last time you had a relapse of your IBD, how long did it take to get to see your specialist?	
1-2 days	75 (28.7)
3-5 days	56 (21.5)
6-14 days	60 (23.0)
More than 14 days	70 (26.8)
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	199 (76.2)
No	45 (17.2)
Unsure	17 (6.5)

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

Suspicion of IBD mostly resulted in a referral to a paediatric gastroenterologist (61.7%) in the first instance and, less frequently, a gastroenterologist (15.2%) or paediatrician (13.6%, Table 8). Youth aged 16 and 17 were more commonly referred to a non-paediatric gastroenterologist (26.7% vs. 9.2%) and less frequently a paediatrician (8.9% vs. 16.1%) or paediatric gastroenterologist (56.7% vs. 64.4%) compared to younger youth. Youth admitted to overnight inpatient care in the past year (n = 98) were predominantly cared for in paediatric gastroenterology wards (63.9%) and alongside children of all ages (81.4%, see *A8 & A10: Inpatient facilities & care*). Respondents commonly received printed information about IBD (80.2%), however, many believed that the material was unsuitable for a child (41.8%) (Table 9). Almost half of 16/17-year-olds and parents/carers of youth in this age group (45.0%) indicated either no discussion about the youth's transition to adult care (41.6%) or were unsure if one had occurred (3.4%) (Table 8).

Table 8 First referral upon suspicion of IBD by youth age at diagnosis

	n (%)		
	Age at diagnosis [#]		
When IBD was first suspected, who did the doctor first refer the youth to?	Under 16	Age 16/17	All ages
Paediatric gastroenterologist	112 (64.4)	51 (56.7)	163 (61.7)
Gastroenterologist	16 (9.2)	24 (26.7)	40 (15.2)
Paediatrician	28 (16.1)	8 (8.9)	36 (13.6)
Other	17 (9.8)	7 (7.8)	24 (9.1)
Unsure	1 (0.6)	0 (0.0)	1 (0.4)
Discussion about the youth's transition to adult care	Age 16/17 [#]		
Yes	49 (55.1)		
No	37 (41.6)		
Unsure	3 (3.4)		

Approximated in parent/carer responses from birth, diagnosis and survey years.

Table 9 Arrangements for the care of children and young people who have IBD

	n (%)
Has the youth ever been given printed information about Crohn's or colitis?	
Yes	207 (80.2)
No	41 (15.9)
Unsure	10 (3.9)
If so, the printed information was appropriate for:	
Both child and parent/carer	112 (54.4)
Parent or carer	84 (40.8)
Child	8 (3.9)
Neither	2 (1.0)

A13: Psychological care

Psychological burden was high among youth, as indicated by the rate of elevated mood and anxiety disorder risk in in both parent/carer-provided reports (48.8%) and direct responses from 16/17-year-olds (61.5%) (Table 10). A quarter of youth (25.1%) were engaged in mental health support from a health professional, most commonly on a monthly (35.9%) or fortnightly basis (26.6%) and with a psychologist (78.1%) or GP (25.0%). Although over two-thirds (68.8%) were satisfied with their mental health treatment, a minority (29.7%) believed it was easy to access mental health services (Table 11). Many respondents (77.4%) agreed that mental health expert was an important part of managing the youth's IBD, but few (27.8%) reported the availability of such support in their IBD service (Table 11). Similarly, over half of the respondents (62.4%) had not been asked about the youth's mental health by a health professional in the previous 12 months, most of whom would have preferred to have been asked (78.3%). Many respondents (82.7%) similarly believed that the youth's gastroenterologist or IBD nurse should query mental health concerns. However, comparatively fewer (56.7%) agreed that they have (or would) find it easy to seek mental health support via their gastroenterologist or IBD nurse.

Table 10 Mental health characteristics and support

	Mean (SD), range
Youth psychological burden	
Parent/carer-reported youth psychological burden (PSC-17)	4.4 (2.6), 0-10
16/17-year-olds (K10)	25.5 (11.3), 10-50
	n (%)
High youth psychological burden	
Parent/carer-reported youth psychological burden (PSC-17 internalising \geq 5)	104 (48.8)
16/17-year-olds (K10 total \geq 20)	24 (61.5)
Is the youth seeing anyone currently for any mental health issues/stress?	
Yes	64 (25.1)
Psychologist	50 (78.1)
GP	16 (25.0)
Counsellor	12 (18.8)
Psychiatrist	11 (17.2)
Social worker	11 (17.2)
Nurse	3 (4.7)
Other mental health professional	1 (1.6)
How often does the youth meet with their primary mental health expert?	
Weekly	9 (14.1)
Fortnightly	17 (26.6)
Once a month	23 (35.9)
Other (please specify)	15 (23.4)
Is the youth satisfied with the treatment for their mental health issues?	
Yes	44 (68.8)
No	11 (17.2)
Other (please specify)	9 (14.1)

Approximately a third (35.1%) of respondents were asked about any youth mental health concerns by their hospital care team in the previous year, with around one in five youth accessing mental health support during their stay (20.6%) (see Appendix 2).

Table 11 Mental health care queries, support-seeking, and attitudes

	n (%)
While meeting with their gastroenterologist, IBD nurse or other health professional in the past 12 months, have they asked about any mental health concerns for the child (even if not related to their IBD)?	
Yes	92 (36.1)
No	159 (62.4)
Other (please specify)	4 (1.6)
If no, would the youth or parent/carer have liked to be asked about any mental health issues for the youth?	
Yes	130 (78.3)
No	26 (15.7)
Other (please specify)	10 (6.0)
Does the youth have access to a mental health expert (e.g., psychologist, psychiatrist) as part of their IBD service?	
Yes	71 (27.8)
No	152 (59.6)
Other (please specify)	32 (12.5)

Gastroenterologist or IBD nurse should ask about any mental health concerns (even if not related to their IBD).	
Yes	211 (82.7)
No	34 (13.3)
Other (please specify)	10 (3.9)
I believe having access to a mental health expert (e.g., psychologist, psychiatrist) is an important part of managing my/their IBD.	
Strongly agree	148 (58.0)
Agree	75 (29.4)
Neither agree nor disagree	27 (10.6)
Disagree	3 (1.2)
Strongly disagree	2 (0.8)
It was easy to access mental health services (i.e., psychologist, psychiatrist).	
Strongly agree	9 (14.1)
Agree	10 (15.6)
Neither agree nor disagree	16 (25.0)
Disagree	13 (20.3)
Strongly disagree	16 (25.0)
I have found it easy (or would find it easy) to talk to my/their GP about seeking mental health support (for the youth).	
Strongly agree	68 (26.9)
Agree	91 (36.0)
Neither agree nor disagree	59 (23.3)
Disagree	29 (11.5)
Strongly disagree	6 (2.4)
I have found it easy (or would find it easy) to talk to my/their gastroenterologist/IBD nurse about seeking mental health support (for the youth).	
Strongly agree	62 (24.4)
Agree	82 (32.3)
Neither agree nor disagree	66 (26.0)
Disagree	32 (12.6)
Strongly disagree	12 (4.7)

A series of comparisons were conducted between youth with high and low psychological burden using the cutoff values for an elevated risk of mood and anxiety disorder (see Table 10 for cutoff values). Pooled comparisons using both parent/carer reports (PSC-17 internalising subscale) and direct responses from 16/17-year-olds (K10) found youth in the high burden group more likely to be female, aged 16 or over, have active IBD (Manitoba Index, PRO3), have received past-year overnight inpatient care, more likely to be currently engaged with mental health support, and to report greater use of opiate and mental health medications (Table 12). Independent analyses of 16/17-year-olds further found lower current biologic medication use among the high burden group (see Appendix 3). High psychological burden youth and the parents/carers of youth that met this threshold (i.e., the pooled *high youth psychological burden* group) were also less likely to report a plan with their IBD treatment team in case of IBD worsening or side effects, a planned annual review, or 'completely' detailed explanations of care and treatment options. Additionally, this group less frequently reported 'completely' detailed answers to IBD-related questions asked of their specialist doctor, pharmacist, or psychologist. Independent comparisons of 16/17-year-old and parent/carer respondents are presented in Appendix 3.

Table 12 Comparison of youth with **high (%)** and low (%) psychological burden from pooled 16/17-year-old and parent/carer-reported symptoms

Demographics	High (%) / low (%)
Gender – Female	60.2 vs. 36.3***
Age ≥ 16 years	40.6 vs. 27.4*
Clinical characteristics	High (%) / low (%)
Active IBD - Manitoba Index	75.4 vs. 57.7**
Active IBD - PRO3 (Crohn's disease)	58.2 vs. 25.7***
Past-year overnight inpatient care	44.4 vs. 31.7*
Current opiate medication	7.2 vs. 0.8*
>6 weeks opiates past-year	8.0 vs. 0.8**
Current mental health medication	16.5 vs. 4.0**
> 6 weeks mental health meds past-year	15.7 vs. 2.4***
Current mental health support	40.6 vs 8.1***
Care quality/information & education	High (%) / low (%)
Plan with IBD team for worsening disease/side effects – 'Yes'	51.6 vs. 64.5*
Member of IBD team explained care/treatment options – 'Yes, completely'	43.0 vs. 58.5*
Planned annual review – 'Yes'	74.2 vs. 84.7*
Enough information from IBD-related queries– 'Yes, completely'	
Specialist doctor	47.2 vs. 61.3*
Pharmacist	20.0 vs. 39.7*
Psychologist	22.0 vs. 56.0**

Standard B: Local delivery of care

B1: Arrangements for shared care

Although more than half of respondents (53.6%) had a GP involved in their IBD care, around one-fifth of this group (19.3%) were unclear on or unsure about the issues for which specialist or hospital care should be sought (Table 13). Additionally, over a third (36.4%) either thought their GP was not informed of results and treatment in the speciality or hospital care setting or were unsure if they were.

Table 13 GP shared care

	n (%)
Is their GP involved in the youth's IBD care?	
Yes	140 (53.6)
No	107 (41.0)
Unsure	14 (5.4)
If yes, are you clear on what issues you/they should seek specialist/hospital care for?	
Yes	113 (80.7)
No	14 (10.0)
Unsure	13 (9.3)
Do you think the GP is kept informed about results and treatment by the specialist/hospital?	
Yes	166 (63.6)
No	49 (18.8)
Unsure	46 (17.6)

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

Most respondents (76.3%) had access to a phone or email helpline where a response was received by the end of the next day (Table 14). While just over half of respondents (55.9%) believed they had a choice in IBD treatment, many did not, were unsure, or never asked (25.7%), and over half (59.8%) wanted more involvement in decisions about care and treatment. A large proportion of respondents (70.9%) reported that they had been given a choice in their follow-up care or were happy with it despite not being offered a choice in how it was delivered. Nevertheless, around one quarter (26.1%) wanted a choice in follow-up care delivery but were not offered one. While approximately one-fifth of youth (19.9%) were taking complementary therapies, a minority of the total sample (26.1%) reported the youth's treating doctor querying their use. Few respondents (18.4%) reported being asked to provide feedback on their IBD care (e.g., survey, feedback card, web form, open day).

Table 14 Patient centred services

	n (%)
Does the youth's IBD treating team provide access to an email or telephone help line where you/they get a response by the end of the next day?	
Yes	199 (76.2)
No	45 (17.2)
Unsure	17 (6.5)
Do you have a choice in what treatment you/they have?	
Yes	146 (55.9)
No	29 (11.1)
I'd rather the doctor decided	48 (18.4)
Unsure/I've never asked	38 (14.6)
Do you want to be more involved in decisions about your/their care and treatment?	
Yes	156 (59.8)
No	67 (25.7)
Unsure	38 (14.6)
Do you/they use any complementary therapies (i.e., not prescribed by their treating team e.g., supplements or mind-body therapies)?	
Yes	52 (19.9)
No	193 (73.9)
Unsure	16 (6.1)
Has your/their doctor asked what complementary therapies you/they use, if any?	
Yes	68 (26.1)
No	173 (66.3)
Unsure	20 (7.7)
Have you been given a choice on how you/they participate in follow up care (i.e., out of hospital care, e.g., specialist rooms, outpatient clinic, GP shared care, or telehealth)?	
Yes	96 (36.8)
No, I'd like a choice	68 (26.1)
No, but I'm happy with the way follow up care is delivered	89 (34.1)
Unsure	8 (3.1)
Have you ever been asked for feedback about your/their IBD care such as a survey, feedback card, web form, open day?	

Yes	48 (18.4)
No	203 (77.8)
Unsure	10 (3.8)

Standard D: Patient education and support

D1: Provision of information

Although almost all respondents (95.7%) reported that their care and treatment options were explained to them, a third (33.9%) did not have an agreed plan with their treatment team in the event of worsening symptoms or adverse treatment side effects (Table 15).

Parents and carer responses suggested that the IBD treatment team offered opportunities for the youth's involvement in education and information sharing comparatively less frequently (54.8%) than offered to parents and carers (80.5%). Printed IBD information provided to respondents was also less regularly accommodating to youth (58.3%) than their parent or carer (95.2%).

Table 15 Provision of information

	n (%)
Has a member of your/their IBD treatment team explained your/their care and treatment options?	
Yes, completely	131 (50.8)
Yes, to some extent	116 (45.0)
I didn't need an explanation	1 (0.4)
No	10 (3.9)
Does your IBD treating team provide an opportunity for your family/carer to be involved in education/information sharing?#	
Yes, completely	23 (56.1)
Yes, to some extent	10 (24.4)
No	5 (12.2)
No need to be involved	3 (7.3)
Has their IBD treating team provided an opportunity for the child to be involved in education/information sharing?##	
Yes, completely	50 (23.0)
Yes, to some extent	69 (31.8)
No	93 (42.9)
No need to be involved	5 (2.3)
Have you/they ever been given printed information about Crohn's or colitis?	
Yes	207 (80.2)
No	41 (15.9)
Unsure	10 (3.9)
The printed information was appropriate for:	
Both child and parent/carer	112 (54.4)
Parent or carer	84 (40.8)
Child	8 (3.9)
Neither	2 (1.0)
Do you have an agreed plan with your/the IBD treating team about what to do if your/their symptoms worsen, or you/they experience treatment side effects?	
Yes	147 (57.2)
No	87 (33.9)
Unsure	23 (8.9)
#16/17-year-old respondents only (n = 41)	
##Parent/carer respondents only (n = 217)	

Among youth who had used oral steroids for any duration (n = 191), 83.2% of respondents received an explanation of short- and long-term side effects (Figure 6).

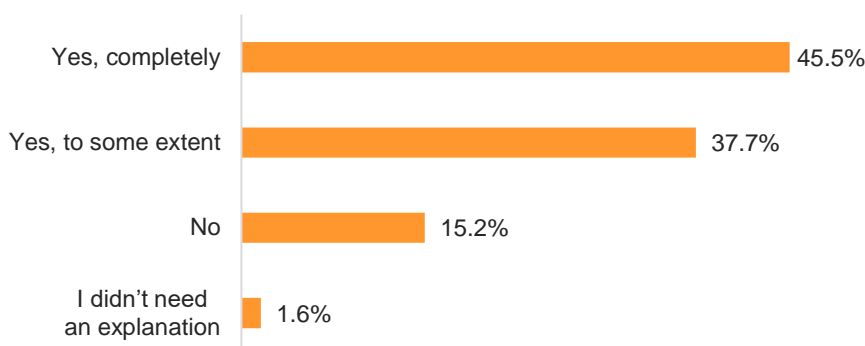


Figure 6 Explanation of short- and long-term side effects related to the youth's oral steroid use

Respondents most reported getting sufficiently detailed responses to IBD-related questions asked of their specialist (89.8%), IBD nurse (88.7%), and dietitian (78.9%, Table 16)

Table 16 When you had IBD-related questions to ask your/their healthcare provider, did you get enough information?

n (%)	Specialist	GP	Dietitian	Pharmacist	IBD nurse	ED staff	Psychologist
Yes, completely	137 (53.7)	47 (19.0)	70 (42.2)	43 (20.0)	120 (58.5)	20 (11.7)	24 (23.5)
Yes, to some extent	92 (36.1)	77 (31.0)	61 (36.7)	76 (35.3)	62 (30.2)	65 (38.0)	17 (16.7)
No	23 (9.0)	52 (21.0)	27 (16.3)	25 (11.6)	13 (6.3)	55 (32.2)	27 (26.5)
I had no need to ask	3 (1.2)	72 (29.0)	8 (4.8)	71 (33.0)	10 (4.9)	31 (18.1)	34 (33.3)

The provision of information standard was further assessed for all respondents indicating past-year overnight youth inpatient care (35.1%)(see Appendix 2). While around half of respondents (50.5%) reported being 'completely' informed of post-discharge illness or treatment-related danger signs to be mindful of, nearly a fifth (18.6%) indicated that no such information was offered. Additional data regarding the provision of information in inpatient care is presented in Appendix 2.

D2: Education for patients

While most respondents (79.4%) did not report an opportunity to attend an IBD educational forum (Table 17), the large majority (81.0%) of those afforded the choice chose to participate.

D3: Patient-support groups

Fewer than half of respondents (48.2%) reported being told by a health professional how to find a Crohn's or colitis patient support organisation (Table 17). There was a near-even split between those who regularly accessed online IBD forums or websites for information (49.4%) and those who did not (49.8%). Very few respondents (8.6%) indicated they had been offered an opportunity to attend an IBD children's camp or activity day, however, offerings for these events in Australia have been limited since late 2019 after the emergence of the COVID-19 pandemic.

Table 17 Education and support groups

	n (%)
Have you ever had the opportunity to attend an IBD educational forum?	

Yes	42 (16.3)
No	204 (79.4)
Unsure	11 (4.3)
If yes, did you attend?	
Yes	34 (81.0)
No	8 (19.0)
Has a health professional ever told you how to find a Crohn's or colitis patient support organisation?	
Yes	110 (43.1)
No	123 (48.2)
Unsure	22 (8.6)
Have you/they ever had an opportunity to attend an IBD children's camp or activity day?	
Yes	22 (8.6)
No	228 (89.4)
Unsure	5 (2.0)
Do you regularly access online IBD forums or websites for IBD information?	
Yes	126 (49.4)
No	127 (49.8)
Unsure	2 (0.8)

Standard F: Evidence-based practice and research

F2: Research

Very few respondents (7.8%) reported the youth had an opportunity to be treated via a research trial (Table 18), though nearly all youth afforded the opportunity opted to participate (90.0%).

Table 18 Research

	n (%)
Have you/has the child ever been offered the opportunity to receive treatment through a research trial?	
Yes	20 (7.8)
No	228 (89.4)
Unsure	7 (2.7)
If yes, did you/they participate?	
Yes	18 (90.0)
No	2 (10.0)

Geographical remoteness observations

Several statistically significant differences emerged in comparisons based on participants' geographic distribution. Those living in regional and rural areas were more likely to report active IBD (77.3% vs 62.8%), current steroid use (18.6% vs. 9.0%), and no explanation of short- and long-term steroid side effects (17.9% vs. 9.0%) compared to respondents in major cities. They were also more likely to be unsure if there was a planned annual IBD review with their specialist (22.1% vs. 10.5%) and less likely to report the opportunity to attend an IBD educational forum (6.0% vs. 19.7%). Findings trended toward greater psychological burden among youth in regional and rural areas but yielded no statistically significant differences among parent/carer (PSC-17 46.5% vs. 54.5%) or 16/17-year-old respondents (K10: 57.1% vs. 70.0%).

Table 19 Comparison between youth living in major cities vs. regional/rural areas

	Major city n (%)	Regional/rural n (%)
Manitoba Index		
Active IBD	115 (62.8)	51 (77.3)*
Current steroids		
Yes	17 (9.0)	13 (18.6)*
Steroid side effects explained		
No	17 (12.4)	12 (24.0)#
Planned annual review		
Unsure	20 (10.5)	15 (22.1)*
Opportunity to attend IBD educational forum		
Yes	37 (19.7)	4 (6.0)**

* $p < .05$, ** $p < .01$, # $p = .053$

Perspectives on improving paediatric IBD care

Respondents were invited to suggest improvements in paediatric IBD care through the open-text prompt: *What changes would you make to improve the healthcare for your/the child's IBD? What are your reasons?* Individual comments were coded and grouped into the following themes (full results table in Appendix 4).

Access to a skilled multidisciplinary team (n = 73)

The accessibility and skill of a multidisciplinary IBD treatment team emerged as the most prominent theme overall. Better access to mental health support featured prominently in these responses (n = 26), including improved access to mental health support (n = 18) and implementation of mental health screening in IBD care (n = 5). Other respondents wanted greater access to a dietitian (n = 9) and IBD nurse (n = 7). Better IBD-related skills and knowledge were also desired for mental health professionals (n = 3), emergency department staff (n = 3), GPs (n = 2), and dietitians (n = 2).

Health professional communication (n = 68)

Suggestions to improve communication by healthcare professionals with patients and with other healthcare professionals were almost as common as those related to multidisciplinary care. Most commonly, they related to listening to and addressing the personally expressed issues of the patient (23), such as explaining and acknowledging eating, symptom and emotional challenges, as well as discussing test results and complementary therapy. Responses underscored a desire for greater parent co-participation and education in consultations (n = 12) and age-appropriate communication and informational resources for youth (n = 8). Several responses wanted a written IBD management plan (n = 9).

Improved communication between members of the treating team was also sought (n = 11), including the relationship between the GP and specialist team (n = 3) and providers across the public-private health services (n = 3). Further, some felt they received conflicting information between youth treatment team members (n = 3).

Accessible and timely specialist review and out-of-consultation advice (n = 56)

A substantial proportion of comments indicated a need for timely access to specialist review (n = 17). Suggestions included extended clinical hours (n = 7) and better facilitation of appointments for urgent reviews of the youth's IBD (n = 4). Others sought greater access to specialist care in regional and

rural areas (n = 6) and the coordinated scheduling of consultations, tests, and treatments for greater convenience (n = 4).

Several respondents wanted a phone or email contact point for out-of-consultation advice (n = 11).

Similarly, others wanted these services to be faster or more responsive (n = 4) and have greater hours of availability (n = 3).

Social support and community awareness (n = 25)

Respondents sought relatable social connections with others going through IBD care, including youth-to-youth (n = 7) and parent support groups (n = 4). Likewise, others wished for greater recognition and understanding of IBD's impact from the youth's school (n = 4; e.g., absences) and community awareness of IBD in general (n = 2).

Improved diagnosis and clinical management (n = 12)

Some responses underscored a desire for non-specific improvements in IBD care, including faster diagnosis (n = 5) and better treatments and management of IBD in general (n = 5). Others specifically wished for better options to manage IBD through dietary means (n = 2).

Facilities and costs (n = 8)

A handful of respondents (n = 4) wanted a reduction of care-related costs (e.g., private healthcare and faecal calprotectin tests). Respondents also sought improvements in inpatient facilities and care arrangements (n = 4), such as the youth's access to their own room or toilet and hospital-in-the-home care.

Family Interview Findings

A total of 35 family interviews were undertaken with an average duration of 59 minutes. Youths mostly participated with their mother, and less frequently, their father or siblings. Participating IBD youth had an approximate average age of 12 years and ranged from 6 years to 17 years. There was a greater representation of males (62.9%). Families reported diagnoses of Crohn's disease (n = 18), ulcerative colitis (n = 11), and IBD unclassified (n = 3).

Before 'IBD': The path to diagnosis, pain, and trust in the healthcare system

The lead-up to the youth's diagnosis emerged as a persistent theme throughout the interviews despite no direct prompt from interviewers. This period evoked strong and explicitly negative sentiments for several families, often characterising their experience as a "long", "frustrating", and emotionally draining "fight" with healthcare providers for action:

"We find that they, they didn't listen to us throughout the journey, you know? We kept saying constantly, she's nauseous, she's nauseous. This is not right. It's debilitating for her, but sort of nothing was done in that regard [...] this wasn't just weeks, you know, this is, you know, 8, 9, 12 months, you know, so. We found it rough."

– Mother of a 14-year-old living with Crohn's disease

Some families described the lead-up to diagnosis in more invalidating terms, feeling that healthcare providers did not believe them or trivialised their concerns:

"Yeah. I don't know, but I kind of knew something was definitely wrong with his digestive system because I had a problem like this myself when I was pregnant with [youth], and it ended up taking three years to get an answer ... [Youth: I feel like they just felt like I was lying.]"

– Mother of a 16-year-old living with Crohn's disease

"...you know, we were going along and I just kept getting told she wasn't sick compared to, um, other people [...] and to watch a child sort of suffer every day, it's not nice being told that."

– Mother of a 14-year-old living with Crohn's disease

Descriptions of the diagnostic process from parents described helplessness, being uninformed about diagnosis, misdiagnoses and repeat visits to healthcare providers without satisfactory answers:

"I would say, like there are many good doctors as well, but some, I think they don't have a maybe proper knowledge of IBD. We got pushed back many, many times when we started by hospital staff for doctors and nurses. 'No, no, no. It's a gastro. Go home, go home.' [...] It was, it was quite confusing, honestly, and there were so many times when we felt like maybe it's a misdiagnosis. They couldn't diagnose what the problem is. It's just trial and error on my kid. Yeah, it was not easy anyway. When you get all of a sudden, all the things."

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

One mother described repeat misdiagnosis resulting in the youth's admission to inpatient care after initiating a laxative regimen intended to treat constipation:

"So, we went to two or three doctors and they all said it was constipation. And then one, like and then we went through one more and he said it was like IBS [...] it just so happened that the day he was supposed to get the colonoscopy just for exploratory, he was actually in hospital anyway from just being so sick, so [...] It was hell. It was really hard."

– Mother of a 12-year-old living with Crohn's disease

Parent accounts of their journey to a diagnosis often reflected a pronounced sense of urgency and punctuated with references to the child's severe symptoms and physical deterioration. Several parents felt that the youth had to get "sick enough" before any progress towards a diagnosis:

"I found it frustrating when we first started on board. Um, no one picked up on this, which was fine, I understand, but we got told, 'Wait, wait, let's see what happens.' And, you know, the weight was dropping off her and you could clearly see something was wrong, to the point

where it got urgent and months later it was sort of too late, and then hospitalisation and feeding tube and all that kind of stuff.”

– Mother of a 14-year-old living with Crohn's disease

“...it was only after [youth] had sort of a 10-day stay in hospital that the paediatrician there pushed for some attention from [hospital] and that's when things started moving. So, he had to get to a certain point of sickness before he could get... He was very, very unwell before we could get some action.”

– Mother of a 15-year-old living with Crohn's disease

One mother described the journey to a diagnosis as living in a “no man's land” while the youth's normal life came to a standstill:

“I think I found it sort of more frustrating, I'd say with doctors, it wasn't the explanation of things, it was more trying to get something done. [Interviewer: Yeah. Yeah. Did you feel like you had to push for that?] Yeah, constantly. Just sitting, sitting in no man's land and having, you know, she's not sick enough, but, you know, but she, she was not living life, and, so we-, we really found that frustrating in the end.”

– Mother of a 14-year-old living with Crohn's disease

Accessing appropriate care: a country-city divide

Interviews with several families from regional or remote areas and cities less access to specialist care reflected a strong perception of disparity between the IBD care available locally and in major cities. Many families described their local healthcare services as under-resourced, offering limited support or access to multidisciplinary specialist care:

“We, we come from a country hospital, which is pretty appalling, so going into [metropolitan hospital] is really nice. There's lots of stuff there. I was shocked at you know, just the quality of everything, you know, it was all nice and there's so much to offer for the kids there in the hospital and yeah, it was just amazing. [Interviewer: So how does that compare to the one in your town?] It doesn't compare, at all.”

– Mother of a 14-year-old living with Crohn's disease

“They've all been like offered to me [multidisciplinary specialists]... but once we are home and in the [local] region, there's really nothing”

– Mother of a 16-year-old living with Crohn's disease

Families living in non-metropolitan areas often expressed their dissatisfaction with their care in relation to unmet information needs, including a desire for better IBD knowledge among local healthcare providers, greater patient education, and more accessible specialist advice:

“Uh, well, I've always found that they're like, the specialists in [major city] and the nurses in the IBD clinic, they're like quite helpful and they know how to answer the questions, whereas doctors here, they just, they don't know much about it.”

– Mother of a 14-year-old living with Crohn's disease

“If we had an IBD clinic, a proper clinic with support staff in [local region], that would be better. But it's really just [local specialist] on her own and us trying to muddle through work it out ourselves. So, there's not a lot of supports for families. There wasn't anyone that could sit down with [youth] and say ‘right this is what's going to happen when you have your colonoscopy’ other than me.”

– Mother of a 15-year-old living with Crohn's disease

“The barriers of having, being in [local region] are really, really tricky. It is, it's really tricky and we do battle with that. I think what would be fantastic, is just to have the nurse or somebody that is just... that go to that you can ask anything to.”

– Mother of a 6-year-old living with Crohn's disease

A lack of appropriate specialist care locally often necessitated complex care processes involving long-distance travel by car or air and shared-care arrangements between local and non-local healthcare providers:

“So, you know, by the time you drive there and then you, you're waiting around, you're trying to get out of the city again to drive all the way home. And I mean, that can be obviously quite frustrating as well [...] I mean, I just find it a bit difficult driving over night because I'm a bit of a blind as a bat, but you know, you got to stay overnight, take extra day off work”

– Mother of a 14-year-old living with Crohn's disease

[metropolitan hospital] are overseeing all of our treatment and care, but we have a local regional hospital. [...] And we have well, we have now, we didn't initially, but we now have a paediatrician that's sort of like our in between, go to, middle person. So, she sends a lot of our inquiries or questions to [metropolitan hospital to get them answered because she gets a much quicker and easier response than us hassling them all the time.”

– Mother of a 6-year-old living with Crohn's disease

The burden of diagnostic and treatment procedures

Many families described the experience of diagnostic and treatment procedures as physically and psychologically stressful. These experiences spanned a range of procedures, including inserting needles and cannulas, drinking bowel-preparation solutions, surgery, and imaging procedures (e.g., MRI). Adverse accounts of first-time procedures at diagnosis and during the early treatment period were particularly common and often formative events in the youth's apprehension toward later treatment:

“So it's a bit invasive for him because they brought the jug out and like, “can you drink this?” And like, the given how he lost so much weight, he lost 20% of the body weight at the time and they had like 500 mls of this prep, whatever it's called Prep fleet. Whatever it's called. And um it's just I think for him it's him, he welled up and started crying straight away. He's like he's, cause I think he had flashbacks from when he first had his colonoscopy.”

– Mother of a 12-year-old living with Crohn's disease

“No, I had never had an MRI before. Yeah, it was a terrible experience [...] I needed the child life therapy to do the first few because of the experience I had at [hospital].”

– Mother of a 15-year-old living with Crohn's disease

Youth often discussed adverse experiences in terms of confusion, unclear expectations, or a lack of pre-procedure information. Conversely, procedures were described as becoming less threatening with routine and a growing sense of familiarity:

“But, once it like I was there, I was, like, really scared because I didn't know, like, I knew what was going to happen, but I didn't know in a sense. I don't know how to explain it.”

–15-year-old living with Crohn's disease

“I think that they really didn't, um, explain to [youth] what was happening with the gastric tube. They just, they put him to sleep because they're hard to put in. And then he woke up with the tube in and he was quite panicked.”

– Mother of a 9-year-old living with Crohn's disease

“...I wasn't that scared because I knew what was, what to expect. I was like, ‘Well, it's the same as last time, it's the same thing’. I was more relaxed because, like, I've done it before, I can do it again. It's the same thing.”

–15-year-old living with ulcerative colitis

“I think the very first one she had when she was first diagnosed, that was, you know, harder because it was all new and things. But, I think she's had so many scopes, like probably sometimes she's had two a year. Um, so she's quite, now she knows exactly what to expect with the prep the next day when we go to hospital, how it all works.”

– Mother of a 12-year-old living with ulcerative colitis

Families described diverse experiences regarding providers' sensitivity and responsiveness to the youth's discomfort during procedures. Providers' efforts to ease the burden on youth through emotional support, familiarisation, and distraction were often described as helpful and met with gratitude:

“He actually went into a simulated machine, an MRI machine, before he had the actual real one. [Interviewer: Yes] So, that he had an understanding. He's sort of always been the kid that's, um, he likes to know. Knowledge is power for [youth]. Um, and, you know, they were there holding his hand all, you know, on the day of the procedures, but now he's, they've helped him so much that [youth] can tackle these things all by himself.”

– Mother of a 15-year-old living with Crohn's disease

“They actually had me in the operating room. [Interviewer: Really?] So, I'm with him right up until he's completely unconscious and then I left [...] So he doesn't have to face it on his own or anything like that. [Youth: But that was only when, like I had my very first one, so yeah. I wouldn't need it anymore] He reckons he doesn't need me now.”

– Mother of a 16-year-old living with Crohn's disease

Families' accounts of profoundly traumatic experiences were often characterised as an intersection of stressors, typically the combination of a severe disease state, procedures with a higher likelihood of discomfort (e.g., nasogastric tube insertion), and an insensitivity from providers to the youth's distress. A father of a four-year-old undergoing the insertion of a nasogastric tube described the procedure as poorly explained and not undertaken with a “gas” they had been told would be provided:

“Just, well, they made me hold him. [Interviewer: Mhmm.] and the scream that he made, I'll never forget it. So, and that, like I said, it really, yeah, tried me. [...] Everyone in life is busy, but, there's always a but, if you can make life easier by other alternatives, well then just do it.”

Medical consultation: Communicating with youth and family

Discussion of IBD healthcare experiences commonly centred on the family's relationship and interactions with their primary specialist. The youth's role in these consultations and attitude toward their specialist varied widely. Several youth and parents described their specialist as having a warm and personable demeanour, for example, through a relatable or age-appropriate communication style, humour, and efforts to make the appointment “fun”. Others similarly described co-participatory dynamics whereby the specialist addressed the youth directly and encouraged their active contribution to the consultation:

“Even when we're in the hospital. He would talk to [youth], with me there, and then say 'I'm just going to talk to mum for a second'. So he would speak to [youth] first, and then if there was anything else, he would then excuse himself, like get [youth]'s okay, to then just, you know, talk to me about other stuff. He's very good at engaging [youth].”

– Mother of a 12-year-old living with Crohn's disease

“He's nice, he knows what he's doing and he tries to help me understand it. And he's also really relaxing, like, if you're scared while he's doing something. He like, relaxes, you. He's very good at chatter. Like, he's a very good chatter.”

– 12-year-old living with Crohn's disease

Other families perceived their specialist appointments to be blunt and impersonal or predominated by doctor-to-parent interaction:

“She hadn't had any blood tests, no stool samples, nothing, and it was literally within five minutes and we just both just went, (mouth agape), I said 'No, no, no, no, no'. Because she-, I could see her face. She just sort of went, 'Why do I have to do this?' Because we were going, that was our first initial consult with him, and we found that very overwhelming. And since then, she got on the back foot with him. She didn't like it.”

– Mother of a 15-year-old living with ulcerative colitis

“They talk to me a bit more now, but most of the time they talk to mum and dad. I always remember as a little kid, not ever being told anything. They were always asking mum and dad the questions.”

– 17-year-old living with Crohn's disease

Most youths and their parents perceived their specialist as a trusted and preferred source of IBD information, typically with references to accurate or evidence-based knowledge. However, this

information varied widely in its understandability and completeness. Some families described their specialist's information as clear and comprehensive, while others often found it confusing or, in some cases, completely absent:

"Like he won't, you know, just say the bare minimum and then let you guess the rest. He tells you everything you need to know. Which is how I like it. I don't care if it's like the worst news. I just want to know."

– 15-year-old living with Crohn's disease

"No. When I first got my diagnosis, my paediatric gastroenterologist said, 'Do you know what it is?', and we said, 'No.', and he said 'Look it up.'"

– 15-year-old living with ulcerative colitis

Many youths' comprehension of IBD and its treatments was filtered through their parents.

Nonetheless, parents often reported their own confusion in interpreting specialist information.

Mothers, in particular, were commonly described as a chief source and 'translator' of IBD-related information for the youth:

"We used to go to, um, the special appointment with the specialist and we'd come out and I'd tell her, 'Did you understand what the doctor was saying?' And she goes, 'I never understand anything.' I'll just wait until we get back to the car and you can tell me what he said."

– 16-year-old living with Crohn's disease

Confusing or sparse information from the primary specialist compelled several families to use web and social media sources. These sources were typically discussed by parents and youth as accessible and convenient but often perceived as a stopgap solution with unreliable accuracy:

"You've just got millions of questions or something. So it's like, not the best because we've got so many questions, and I'll ask Mum a question and then she'll Google it and give me an answer, and then I'll Google it and get a completely different answer. It's just depending on what website you've got."

– 15-year-old living with ulcerative colitis

One family expressed frustration with a lack of information from their specialist, with the youth describing YouTube her "best friend" in learning about IBD during her flares. She described YouTube as "dodgy", and sometimes distressing, but felt it was "better than nothing":

"I got told like while I was in my flare, if it didn't get better, I would have to get an ostomy. So he was like, 'If you're not going to get any better.' So then, I had a big freak out."

– 15-year-old living with ulcerative colitis

Hospitalisation: Vulnerability and the recognition of family needs in inpatient care

Hospitalisation was a formative experience for many families and emerged as a recurring point-of-reference when discussing their 'overall' attitudes and satisfaction with care. This period marked a transitional milestone for some families, who described the commencement of 'serious' investigations into the youth's ill-health, diagnosis, and a coordinated plan for recovery. Some parents nevertheless described this period as a frenetic or overwhelming, having to learn about a disease they were unfamiliar with while managing the concurrent demands of treatment and the youth's acutely ill health. Family discussion of inpatient care was heavily concentrated on the youth's recollections of this period, commonly the youth's experience of pain, discomfort and immobilisation:

"It's like you're trapped in jail, you cannot leave your room."

–12-year-old living with Crohn's disease

"...I had to sit on a bed all day, watching TV and I couldn't use my right arm or left arm. [Youth's father: Ohh he didn't like having the bung in his arm. (He was) very angry about that]."

– Youth living with ulcerative colitis

"Oh um, so, in the beginning, not eating for three days. I was starving, so, like, and I was just really sad. And having, I was just in a lot of pain too. And it's not I had like a million tubes"

going in my arms and hands. Like there was one on my wrist and it hurts so bad and I couldn't move my arms or anything because it would set off alarms, like on the machine. It was really annoying."

–12-year-old living with Crohn's disease

Youth accounts reflected feelings of fear about the 'unknown', including the procedures that would be undertaken or unfamiliar people involved in their treatment:

"[Interviewer: What were you nervous about?] Youth: It's hospital, what was there not to be nervous about? There was needles everywhere and I was scared what they were going to do to me. I was just nervous." [...] I was in a lot of pain and I was just nervous to what they were going to do. Maybe I didn't want that to happen, because it might have been something bad."

–12-year-old living with Crohn's disease

"Umm but sometimes it's tricky when we go to the hospital though, isn't it? Cause we get all kinds of different doctors? Yeah. So that's sometimes, you know. Hard because you don't have a relationship with them and you kind of seeing a different doctor all the time and especially when [youth] was a little bit younger. I think you were a bit scared some of those times. When we used to go, we used to go to [metropolitan hospital]. And you'd be a bit more nervous, I think, because we'd see different doctors or different doctors would do the operations and stuff. Yeah."

– Mother talking to her 9-year-old living with ulcerative colitis

Explicitly positive and negative sentiments regarding hospital stays commonly related to the hospital environment and interaction with staff. Several families described paediatric hospitals as entertaining to youth, offering stimulating activities and recreational facilities. Staff in these settings were often described as kind, "nice", and responsive to the family's emotional and information needs:

"They were, they were all very caring and, and whatever we needed, you know, whatever questions we had, but I think, we didn't really know what questions to ask [...] but they were-, we couldn't fault them. They were, every single nurse and every doctor that we saw were very, very good."

– Mother of a youth with unclassified IBD

"Even in the corridors getting to like the, the ward in the hospital where in the children's hospital, where they do [youth]'s treatment, you know, we might see his gastroenterologist in the corridor, you know, on her way somewhere else and we'll stop and have a chat. Um, he even sees the nurses, um, in the wards that he's sent to when he's admitted to hospital and, and they know his name. He knows, he knows everyone's name. They all know him. Um, and they'll stop and chat like, you know, how you going, [youth]? What's happening? Where are you up to with your treatment? We can never go into the hospital without running into... [Youth: Someone we know]."

– Mother of a 16-year-old living with Crohn's disease

"I just kind of lost it at that point in time. [...] two of the girls took [youth] aside for me and they played cards with him for probably two or three hours until I was mentally okay to drive home. Cause I knew I wasn't okay to drive home. [...] They are incredible. I was not coping. They gave me space. They let me ring my husband, my mum, everyone I needed to talk, talk it out with and when I was able to, then they played cards with me for a little while. Got me to join the game till they could see I was relaxed and then we went home. But they're amazing. So, that was a safe space for him and for me."

– Mother of a 16-year-old living with Crohn's disease

"They were, they were all very caring and, and whatever we needed, you know, whatever questions we had, but I think, we didn't really know what questions to ask [...] but they were-, we couldn't fault them. They were, every single nurse and every doctor that we saw were very, very good."

– Mother of a youth living with unclassified IBD

Experiences in adult hospital care were less consistent, with some families recounting impersonal, abrasive, or distressing interactions between the family and staff. One youth described her experience

of adult hospitals as “White beds, white room, cranky nurses.” and expressed apprehension about future treatment as an adult:

“That’s what I’m scared about. I’m scared when I go into adults (hospitals), about being stuck in wards with cranky people [...] Because like all the paediatric nurses are like so sweet and so nice. And even if they’re not, they pretend to be, I think and I, yeah, I’m just like, ‘Oh God’.”

– 17-year-old living with Crohn’s disease

One mother of a 16-year-old youth living with Crohn’s disease expressed anger at the family’s treatment by staff in a regional non-paediatric hospital:

“Well, they put the (nasogastric) tube in not too badly the first time, but then overnight, the first night that he had it in, in the night, it slid out and landed on the bed and, and then they accused him of pulling it out and there’s no way he would’ve pulled it out. It had just, the sticky tape had come off his face and it just came out. But they kept telling him he was anorexic and he was this, and we said, don’t you understand it’s Crohn’s, it’s not, he eats, he eats plenty, but he doesn’t keep it in his body.”

– Mother of 16-year-old living with Crohn’s disease

Psychological adjustment, impact and support needs

The psychological impact of IBD emerged as a prominent and recurrent theme for many families, often when discussing periods of severe disease. Families often described managing IBD in terms of isolation. For youth, severe or unpredictable symptoms often resulted in separation from valued people and activities. Youth frequently described long or repeated absences from school, fewer social events, and a reduction or total discontinuation of sport and physical recreation activities:

“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

“It’s like everyone’s progressing [...] and I’m like, well everyone’s 10 million steps ahead of me and I am stuck in my little lonely spot of pothole, so it’s a bit hard.”

– 15-year-old living with ulcerative colitis

The emergence of IBD marked a profound lifestyle shift for many parents. Mothers were most often described by youths as the primary “helper” and responsible for managing the youth’s diet, administering and monitoring medications, coordinating healthcare appointments, liaising with teachers and school administrators, and providing the youth with emotional support. One mother perceived her transition to the role of IBD carer as jarring and struggled to come to terms with the effect on her 15-year-old daughter:

“I was freaked out [...] I’ve never dealt with and, I mean, I feel like I deal with it because I’m the one making all the appointments, going to the doctor, all that sort of stuff. So for me, I’ve never had a, like an illness, like a disease in the family where I’ve had to be conscious of that [...] It was just a shock for me to resign myself to the fact or resolve, should I say resolve the fact that she’s dealing with this. Because I was like, the first thing I said to her was, right, I’m just going to take my colon out and give it to you, and I’ll have a bag. I’m fine with that.”

Although several families wanted greater psychological support, some felt it difficult to access or felt that it was treated as a neglected or secondary concern among those in their IBD treatment team:

“Um, so that, that’s my big thing. That these kids need to be having help in, in the, the minefield of the emotions and the predictions and the thoughts and the worries. You know, that come with all this physical stuff and all the multitude of needles and scans and surgeries and pain and, you know, that, that isn’t really addressed by the doctors because that’s not what they’re there to do.”

– Mother of a 17-year-old living with Crohn’s disease

“You know, the doctors sort of stay in their lane, that's their thing, but a psychologist is a separate thing and I think it would be so helpful if you could have a multidisciplinary [team], and I think that's useful for anyone getting diagnosed with a lifelong chronic illness.”

– Mother of a child living with ulcerative colitis

A desire for psychological support was frequently discussed in the context of diagnosis and the period immediately thereafter. However, some parents sought professional psychological support only to find it unsuitable or perceived their provider as lacking an understanding of IBD:

“I think it's a really big thing when they first get diagnosed and I feel like, you know, we've sort of had to seek that out ourselves, dealing with that [...] which is fine, but often they don't have experience with dealing with chronic illness or that sort of thing. [...] He developed quite severe anxiety at times, not long after her diagnosis, and it took us a lot of different psychologists to find someone to sort of help us manage that. And I think it would've been helpful if there was someone that really had an understanding of what that was.”

– Mother of a child living with ulcerative colitis

Diet: A strategy for control and source of confusion

The interaction between diet and IBD was a recurrent discussion point among parents and youth. Eating “good” or “healthy” foods was the most cited strategy among youths when asked about what they do to “help with their IBD”, and parents frequently described their role in managing IBD in terms of dietary monitoring and management. Eating habits were often discussed in the context of symptom control and ‘trigger’ foods, striking a balance between restriction and ‘normal’ life. Most families described some form of dietary modification, ranging from trivial adjustments to extensive restrictions that profoundly impacted household cooking habits (e.g., cooking separate meals for the youth and family).

Although diet had an implicit sense of importance in managing IBD for many families, the topic frequently elicited a sense of confusion. Families described a range of challenges in their search for dietary clarity, including inconsistent information from different sources, difficulty accessing a dietitian, or receiving general rather than IBD-specific advice:

“...sometimes like all those things are like so overwhelming. Like, you read and someone says, “OK don't eat this,” someone says, “eat this,” Because all it's too much information, at one stage you feel like, nuts.”

– Mother of a 9-year-old with an unspecified IBD diagnosis

“I don't know if there are any dietitians that specialise in IBD, but to have had that opportunity initially would have been brilliant. Um, and we trust our consultant [...] he's been very trustworthy and very good information, but there hasn't been much focus on it. Just really like, ‘no, eat whatever, you'll be fine.’ and then let's move on to the next conversation.”

– Mother of a 6-year-old with Crohn's disease

COVID-19: Disrupted access and the processes of care

The COVID-19 pandemic resulted in a significant shift in the processes of care for many families. Telehealth and videoconferencing became the primary means of specialist consultation for many, though they were seldom discussed in a negative light. In contrast, the closure of state borders or hospital infection control measures were cited by several families as a significant barrier to diagnosis or a disruption to the procedures of their ongoing care.

One mother of a pre-diagnosis 9-year-old youth described distressing repeat visits to hospital emergency after the youth started passing fresh blood during “peak” pandemic and being directed back to the GP that advised them to seek emergency care:

“We went like many times. They always make us sit in a waiting room. They never, like we were waiting for four hours, 5 hours, 6 hours and sometimes, [Youth], he was just, he gets scared. He said, ‘I don't wanna go to hospital, Mama. Whenever I need to go to toilet it's more painful. I can't sit for these long hours’. I had a bit of an argument with the hospital staff over

the phone. And I went there and so many times I was, um, like a I was saying, "I'm not gonna go home. I'm gonna sit here. I'm not gonna go anywhere, you need to check what is happening."

A mother of a 12-year-old youth recounted the hospital delaying the youth's surgery for several months, only for the youth to deteriorate and hospitalised by the surgery's initially planned date:

"...and then COVID hit and she was supposed to have the surgery in [month], then they said, sorry, we have to postpone it till [four months later]. And then her body had a different idea."

One family described needing to get a colonoscopy in a different state as "traumatic" experience:

"They told us, yeah, that we had to stay the night. I had no luggage. They told me I couldn't leave the room, that they weren't providing any food for me. Um, you know, just, it was just a little bit. I wasn't happy with it, and especially when you already have an anxious child that you know. [...] I couldn't walk into the actual theatre with her and it upset her, so she was really crying as I sat in the room and I understand it's COVID and it's, you know, trying times for everybody. Um, that just, I think it was a new procedure for them. So, you know, we had to get COVID tests within 24 hours of presenting but the hospital didn't do them and we had to rely on a public one that never sent results through. And, you know, in the end [youth] was getting COVID tested again. And anyway, it all worked out in the end, but I ended up pulling her out saying, we're not staying. I felt like a bad mother. (Voice breaks, visibly upset)"

– Mother of a 14-year-old with Crohn's disease

One family described the challenge of navigating their hospital's pandemic control measures while tending to the youth's loneliness and need for moral support:

"So, it was one parent at a time. His brother was never allowed up in his room. His family was never allowed up in his room. We had to sneak in his grandparents and his cousins and aunties in the foyer and only if it was a security guard that would allow us to stay. Remember sometimes you had to go outside. I mean that's nothing. That was the COVID experience, unfortunately."

– Mother of a 12-year-old with Crohn's disease

Important Findings

The Paediatric IBD Quality of Care's Patient Experience Survey provides a comprehensive exploration of paediatric IBD care from the perspective of its youth, parent, and carer recipients. Responses reflected care experiences from all Australian states and the ACT with an even gender representation of youth living with IBD. This research complements and underscores several findings from CCA's 2016 survey of patient experiences in adults and older adolescents (16+ years), including a high burden of disease and risk of mood and anxiety disorder, and inconsistent access to multidisciplinary care beyond the primary IBD specialist.

Paediatric IBD care and the COVID-19 pandemic

Family interviews complemented the survey component of this research by affording a flexible exploration of IBD care beyond predefined standards or the typical processes of care. For some families, the COVID-19 pandemic was a central feature of their IBD healthcare experience. Pandemic-related challenges were described at multiple levels of disease and treatment, spanning the entire disease course in some cases. A comprehensive account of healthcare reorganisation and its impact on study participants during this period fall outside the scope of this research and should be considered a report limitation.

The path to diagnosis

The second prominent theme to emerge from the addition of family interviews related to the COVID-19 pandemic's impact on IBD care experiences. These challenges featured prominently in several family interviews and though not directly queried in questionnaires, were endorsed in open-text suggestions for improved IBD care (e.g., "faster diagnosis"). Interviewees described this period as delayed, "frustrating", and often marked by uncertainty, invalidating interactions with healthcare providers, and a severe or worsening symptom burden. While not a primary focus of the survey, interview findings underscore the potential for profound psychological strain during the pre-diagnosis disease period and an eroded trust in the healthcare system well before IBD treatment begins.

"I found it frustrating when we first started on board. Um, no one picked up on this, which was fine, I understand, but we got told, 'Wait, wait, let's see what happens.' And, you know, the weight was dropping off her and you could clearly see something was wrong, to the point where it got urgent and months later it was sort of too late, and then hospitalisation and feeding tube and all that kind of stuff."

– Mother of a 14-year-old living with Crohn's disease

The burden of disease & procedures

The reported rates of active disease, past-year overnight inpatient care, and medication use suggest a high disease burden. Rates of self-reported active IBD ranged from approximately two-thirds of youth at the highest estimate (66.9%; Manitoba Index) to just under half for subtype-specific measures (48.9%; PRO2 - ulcerative colitis, 41.2%; PRO3 - Crohn's disease). Over a third of youth (38.6%) had been hospitalised for overnight care the previous year, around three-quarters of which were unplanned or emergency admissions (76.3%). Additionally, over half of all youth had been escalated to biologic medications (57.6%), and others required opiate pain management (5.7%).

Diagnostic and treatment procedures were often described in interviews as confronting experiences for youth, particularly in the context of the early treatment period, a lack of familiarity, and unclear expectations. Although efforts to reduce youth procedure burden via familiarisation, education, or

distraction were recounted as helpful by some families, others described distressing experiences marked by a perceived insensitivity and non-responsiveness to the youth's discomfort or distress.

Mental health

The psychological strain of IBD emerged as a prominent theme throughout several family interviews and reflected a range of adjustment challenges, including the burden of symptoms, treatment and procedures, social isolation, and disruptive impact on the trajectory of 'normal' life. Mental health support needs were strongly supported by questionnaire data. Greater access to mental health support was the most common change proposed in the questionnaire's open-text query about care improvement.

Quantitative distress measures similarly revealed a highly prevalent elevated risk of youth mood and anxiety disorder from both direct-responding 16/17-year-olds (61.5%) and parent/carer proxy assessments (48.8%). Compared to the most recent Australian Child and Adolescent Survey of Mental Health and Wellbeing,¹⁹ a greater proportion of youth were currently engaged with mental health support at the time of this survey (25.1%) than the total rate of service utilisation for emotional or behavioural problems among 4- to 17-year-olds over a one-year period nationally (17.0%).

Statistical analyses revealed several correlates and potential vulnerabilities to high psychological burden among youth. Youth in the high psychological burden group were more likely to be female (60.2% vs 36.3%), older (i.e., aged 16/17; 40.6% vs. 27.4%), have active disease (Manitoba Index: 75.4% vs. 57.7%, PRO3: 58.2% vs. 25.7%), have received past-year overnight inpatient care (44.4% vs 31.7%) and, respectively, greater and lower use of opiate (e.g., >6 weeks past-year: 8.0% vs. 0.8%) and biologic medications (e.g., current use: 15.7% vs. 2.4%). The experiences of high psychological burden youth and parents/carers of youth in this group also diverged with regard to their interactions with the youth's IBD treatment team. Respondents in the high youth burden group were less likely to report a planned annual IBD review (74.2% vs. 84.7%), a plan in case of the youth's deterioration or medication side effects (51.6% vs. 64.5%), and less likely to indicate a complete explanation of care and treatment options (33.3% vs. 66.7%). Questions related to IBD were similarly less likely to yield a completely detailed response from the youth's specialist doctor (47.2% vs. 61.3%), pharmacist (20.0% vs. 39.7%) or psychologist (22.0% vs. 56.0%). Although high psychological burden was prevalent among youth in this study and frequently coincided with active disease, most respondents reported no mental health query from a health professional in the previous year (62.4%), and less than a third found it easy to access mental health support when sought (29.7%).

"It's like everyone's progressing [...] and I'm like, well everyone's 10 million steps ahead of me and I am stuck in my little lonely spot of pothole, so it's a bit hard."

– 15-year-old living with ulcerative colitis

Multidisciplinary team

Respondents reported an available paediatric gastroenterologist in the youth's treatment team in most cases (89.0%) but access to other specialists was comparatively limited and commonly referenced in open-text suggestions for improving care. Dietitians were reported as available in the treatment team by fewer than half of respondents (47.3%) and, similarly, consulted with youth in inpatient care with marginally greater frequency (49.5%). A specialist IBD nurse was reported available in the youth's treatment team by just over half (52.3%) of respondents and a psychologist by a quarter (25.0%). GPs were involved in IBD care for only around half of the youth (53.6%), although most respondents were clear on issues for which specialist or hospital care should be sought (80.7%). Nevertheless, more than a third (36.4%) either thought their GP was not informed by their specialist or hospital about results and treatment (18.8%) or were unsure if they were (17.6%).

"Uh, well, I've always found that they're like, the specialists in [major city] and the nurses in the IBD clinic, they're like quite helpful and they know how to answer the questions, whereas doctors here, they just, they don't know much about it."

– Mother of a 14-year-old living with Crohn's disease

Paediatric-specific care and the provision of IBD information and education

While most youths were either managed in a paediatric clinic (85.5%) or had a paediatric gastroenterologist available in their treatment team (89.0%), over a third aged under 16 (35.6%) were not referred to a paediatric gastroenterologist when IBD was first suspected. Nearly half (45.0%) of direct-responding 16/17-year-olds and parents/carers of youth in this age bracket reported either no discussion with their treatment team about the transition to adult care (41.6%) or were unsure if it had occurred (3.4%).

Although most respondents reported having their care and treatment options explained to them either 'completely' or 'to some extent' (95.8%), providing IBD information and education was limited in several other areas. Steroids were used by 42.4% of youth overall and by 40.9% for more than six weeks in the previous year, however, around one-in-seven respondents reported no explanation of their short- and long-term side effects. Likewise, approximately a third of respondents (33.9%) reported no plan with their IBD team in the event of worsening symptoms or treatment side effects. Interviews highlighted unmet information needs as a pertinent issue for some youth, though efforts from the treating team to facilitate their active participation in care or provide age-appropriate explanations varied widely between families. Diet information was an area described as inadequate or conflicting among clinicians. Questionnaire respondents similarly reported that printed information about Crohn's and colitis was provided to most (80.2%), but often perceived as not age-appropriate for a child (41.8%). Most 16/17-year-old questionnaire respondents indicated that their treating team offered parent/carer involvement in education and information sharing (80.5%), however, responses from parents/carers suggested these opportunities were less commonly afforded to youth (54.8%). Families were largely receptive to IBD education, with most questionnaire respondents attending an IBD educational forum if they had the chance (81.0%), though few reported being afforded the opportunity (16.3%). Fewer than half of respondents (43.1%) indicated that a health professional advised them on how to find a Crohn's and colitis patient support organisation.

"Like he won't, you know, just say the bare minimum and then let you guess the rest. He tells you everything you need to know. Which is how I like it. I don't care if it's like the worst news. I just want to know."

– 15-year-old living with Crohn's disease

Review and treatment delay

Respondents often lacked or were unsure about access to an email or phone helpline with an end-of-next-day response (23.7%), and open-text suggestions to improve care frequently invoked difficulties accessing specialist advice (e.g., desired phone/email contact point, greater responsiveness, faster advice). The wait for a specialist review upon disease relapse varied widely, with approximately half of respondents (49.8%) reporting waiting times that ranged from one to two weeks (23.0%) to over 14 days (26.8%). Private health services were commonly used for colonoscopy/surgery procedures (42.4%) and radiology services (28.2%) and overwhelmingly motivated by the avoidance of delayed treatment (79.3% and 85.1%).

Person-centred care

Just over half of respondents (55.9%) indicated that they had a choice in what treatment the youth had, and a similar proportion (59.8%) wanted greater involvement in decisions about the youth's IBD treatment. Additionally, around one-quarter (26.1%) felt that they had no choice in how they participated in follow-up care and desired one. Fewer than one-in-five respondents (18.4%) had been asked for feedback about the youth's IBD care. Respondents described positive experiences of empathic, careful communication and interaction with health professionals, but where this was not the case it was a major difficulty for them.

Limitations

The questionnaire methodology of the Patient Experience Survey has several limitations. Self-report disease activity measures offer less reliability than clinical assessment and may reflect gastrointestinal symptoms unrelated to IBD. Additionally, the adult questionnaire used a proxy parent/carer measurement of youth psychological burden (PSC-17) and may be a less sensitive or reliable indicator of psychological distress than direct reports from self-responding 16/17-year-old respondents via the K10. The self-selecting nature of respondents' decision to participate raises the possibility that the youth and parents in the present sample had characteristic differences that reduce the generalisability of findings to the wider IBD population. Youth and parents/carers with more adverse care and treatment experiences or managing a more severe disease course may have been more inclined to participate.

Appendices

Appendix 1 Parent and carer demographic characteristics

n = 221	n (%)
Age - Mean (SD), range (years)	45.8 (5.98), 30-64
Gender	
Female	208 (94.1)
Male	12 (5.4)
I prefer not to answer	1 (0.5)
Highest level of education obtained	
Less than year 12	8 (3.6)
Year 12 or equivalent	37 (16.7)
Vocational education (TAFE)	50 (22.6)
Bachelor's degree	81 (36.7)
Master's degree	23 (10.4)
PhD / doctorate	7 (3.2)
Other (please specify)	15 (6.8)
Marital status	
Single (never married)	3 (1.4)
Married / de facto	198 (89.6)
Divorced	11 (5.0)
Separated	8 (3.6)
Widowed	1 (0.5)
Employment status	
Employed full time	93 (42.1)
Employed part time	73 (33.0)
Self-employed	19 (8.6)
Unemployed and currently looking for work	1 (0.5)
Unable to work	2 (0.9)
Homemaker	27 (12.2)
Retired	1 (0.5)
Student	1 (0.5)
Other (please specify)	4 (1.8)

Appendix 2

Provision of information and mental health support in inpatient hospital care

	n (%)
When you had important questions to ask a doctor, did you get answers that you could understand?	
Yes, always	56 (57.7)
Yes, sometimes	30 (30.9)
No	7 (7.2)
I had no need to ask	4 (4.1)
When you had important questions to ask a nurse, did you get answers that you could understand?	
Yes, always	43 (44.3)
Yes, sometimes	42 (43.3)
No	9 (9.3)
I had no need to ask	3 (3.1)
If you/they have had IBD-related surgery, did you get enough/adequate information before the operation?	
Yes	40 (83.3)
No	4 (8.3)
Unsure	4 (8.3)
Did doctors or nurses give the parent/carer, family, or someone close to the youth all the information they needed to help them recover?	
Yes, definitely	50 (51.5)
Yes, to some extent	36 (37.1)
No	8 (8.2)
No, I didn't want or require information	3 (3.1)
Did someone tell you about danger signals regarding your/the child's illness or treatment to watch for after they went home?	
Yes, completely	49 (50.5)
Yes, to some extent	30 (30.9)
No	18 (18.6)
Did the hospital care team ask about any mental health concerns (even if not related to their IBD)?	
Yes	34 (35.1)
No	60 (61.9)
Other (please specify)	3 (3.1)
Did the youth access mental health support while in hospital?	
No	77 (79.4)
Yes – psychologist	7 (7.2)
Yes – social worker	10 (10.3)
Yes – counsellor	2 (2.1)
Yes – psychiatrist	1 (1.0)

Appendix 3

Comparison of youth with **high (%)** and **low (%)** psychological burden by 16/17-year-old (K10) and parent/carer-reported (PSC-17) youth psychological burden

Demographics	16/17-year-olds[#] High (%) / low (%)	Parent/carer report^{###} High (%) / low (%)	Combined^{###} High (%) / low (%)
Gender - Female	83.3 vs. 26.7^{***}	54.8 vs. 37.6[*]	60.2 vs. 36.3^{***}
Age ≥ 16 years	N/A		40.6 vs. 27.4[*]
Clinical characteristics			
Manitoba Index - Active IBD	87.5 vs. 26.7^{***}		75.4 vs. 57.7^{**}
PRO3 – Active IBD (Crohn's disease)	73.3 vs. 11.1^{**}	53.8 vs. 27.7^{**}	58.2 vs. 25.7^{***}
Past-year overnight inpatient care			44.4 vs. 31.7[*]
Current biologic medication	45.8 vs. 80.0[*]		
Current opiate medication			7.2 vs. 0.8[*]
> 6 weeks past-year		6.9 vs. 0.9[*]	8.0 vs. 0.8^{**}
Current mental health meds		16.3 vs. 2.8^{***}	16.5 vs. 4.0^{**}
> 6 weeks past-year		15.4 vs 0.9^{***}	15.7 vs. 2.4^{***}
Mental health support			
Current youth professional mental health support – 'Yes'	45.8 vs. 6.7[*]	39.4 vs. 8.3^{***}	40.6 vs 8.1^{***}
Care quality/information & education			
Plan with IBD team for worsening disease/side effects – 'Yes'	25.0 vs. 80.0^{***}		51.6 vs. 64.5[*]
Member of IBD team explained care/treatment options – 'Yes, completely'	33.3 vs. 66.7[*]		43.0 vs. 58.5[*]
Planned annual review – 'Yes'			74.2 vs. 84.7[*]
Enough information from IBD-related queries directed at healthcare professionals - 'Yes, completely'			
Specialist doctor	45.5 vs. 93.3^{**}		47.2 vs. 61.3[*]
Pharmacist	9.1 vs. 75.0^{**}		20.0 vs. 39.7[*]
Psychologist		21.9 vs. 52.4[*]	22.0 vs. 56.0^{**}
<small>#K10 total ≥ 20, ###PSC-17 Internalising ≥ 5, ### K10 total ≥ 20 or PSC-17 Internalising ≥ 5 [*] p < .05, ^{**} p < .01, ^{***} p < .001</small>			

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