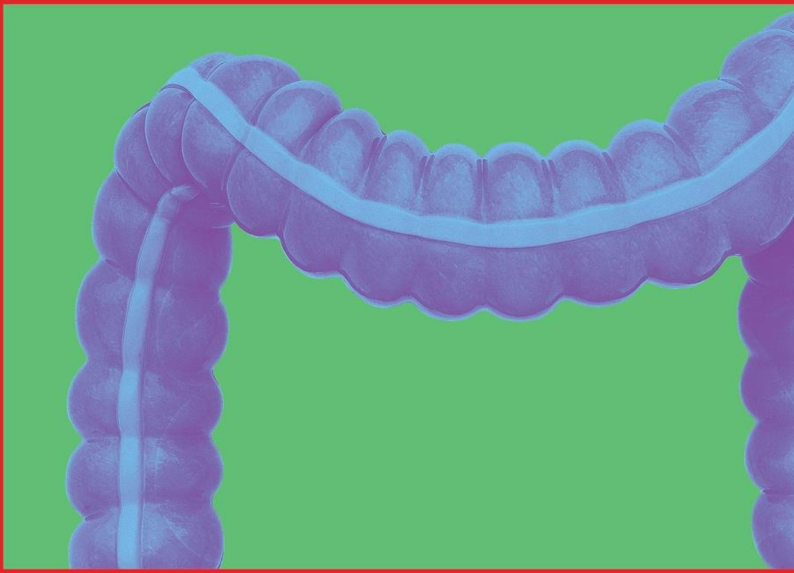
Quantitative short report

Inflammatory Bowel Disease

Patient Experience – Australia



Janssen-Cilag Pty Ltd. ABN 47 000 129 975. 1-5 Khartoum Road, Macquarie Park NSW 2113.
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Background

At Johnson & Johnson, we are leading where medicine is going. Our unwavering commitment to patient centricity is clearly demonstrated in our investment in collaborative research to understand the needs and priorities of patients.

Through collaboration with Patient Organisations, Healthcare Professionals and research organisation Community and Patient Preference Research (CaPPRe) we conducted groundbreaking research with people living with IBD to quantify and map their experiences during their overall healthcare journey. By working across the health ecosystem and consistently focussing on understanding the priorities and unmet needs of patients in Australia, Johnson & Johnson aim to revolutionize the future of healthcare, delivering consistently exceptional experiences that truly empower and support patients.

The results of this quantitative stage, in which participants completed a Best Worst Scaling (BWS) task, generating a patient experience index score (PEI), will be used to understand the patient experience and identify areas of potential improvement, with the aim of providing a consistently exceptional experience. The PEI takes into account both satisfaction and importance, thus providing guidance on areas of the pathway that could be targeted to maximise patient satisfaction - that is, areas that are important to patients, but have lower levels of satisfaction.

Research Aim

To develop a thorough understanding of the patient experience within IBD, specifically Crohn’s Disease and Ulcerative Colitis[1].

Study Objectives

- Identify what is important to patients along the healthcare pathway
- Identify how satisfied patients are with the different areas of treatment and
- care Explore patient beliefs on how IBD healthcare could be improved

Our approach

Methodology

Participants

Patients were recruited through patient support group, Crohn’s and Colitis Australia. Patients were compensated for their time and contribution.

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[1] The current study included patients living with Crohn’s Disease or Ulcerative Colitis and did not explore the patient experience of other types of IBD. Where stated IBD throughout the report, this refers to Crohn’s Disease or Ulcerative Colitis only.

All participants provided consent to participate prior to completing the survey and were able to withdraw at any time without penalty or prejudice, including prior to commencing the survey and during survey completion.

Data was collected between 24-February-2023 and 10-March-2023.

The Survey

Participants completed an online survey which included:

- A Best Worst Scaling (BWS) task
- Socio-demographic questions
- Questions around treatment status and care received

Best Worst Scaling (BWS)

The BWS task used to measure the importance and satisfaction of the different aspects of the healthcare pathway was defined by a master list of 11 'Moments that Matter' (MTM). The MTM were identified through qualitative research from other therapeutic areas, followed by a stakeholder workshop including external key opinion leaders, patient advocacy group members, CaPPRe and Janssen in order to develop and refine the MTM for the current study. A summary of the MTM can be found in Table 1 and on the dashboard information tab (see page 16 for more information).

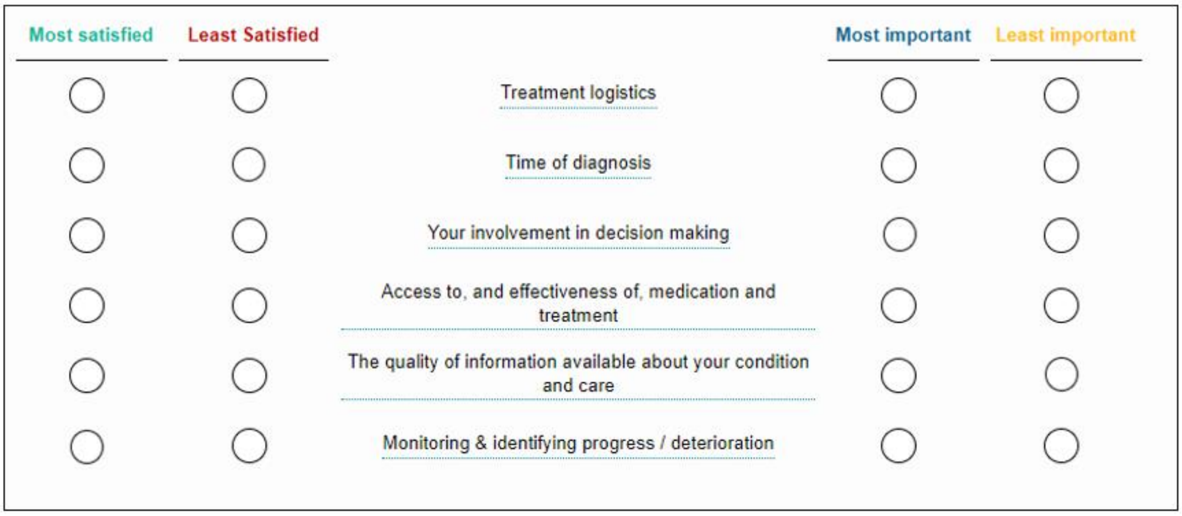
Table 1. PEI MTM and descriptions

	MTM	Description
1	Time to diagnosis	The length of time from developing symptoms, or first consulting with your GP, through to being diagnosed – whatever this looked like for you.
2	The quality of information available about your condition and care	Having clear, concise, relevant information in a format that works for you (e.g., provided to you by your healthcare team/online/Apps/podcasts).
3	Your involvement in decision making	How involved you are in decisions about your treatment and care, e.g., when selecting specific medication and/or when developing a treatment plan.

4	The quality of your healthcare team – access to your key healthcare professional/s, consistency of care, and their communication with you and between each other	Suitable access to your key healthcare professional/s (e.g., gastroenterologist / clinical nurse specialist), at regular intervals that you feel are most beneficial to you or where urgent access is required. Being able to see the same trusted healthcare professional/s on-going for your treatment and care. How well your needs are met in any interactions with your healthcare team (including doctors, nurses, care coordinators). The extent to which different members of your healthcare team (e.g., gastroenterologist / clinical nurse specialist / GP) communicate with each other about your condition and care. They may be healthcare professionals within the same service or in different services.
5	Treatment logistics	The broad impact that following a treatment and care plan has on you., i.e., day-to-day difficulties of arranging and attending treatment sessions.
6	Access to, and effectiveness of, medication and treatment	Your access to medication and treatment for your condition. The effectiveness of your medication/treatment for your condition.
7	Side effects of medication and treatment	Side-effects you may experience from medication and treatment prescribed by your healthcare professional/s.
8	Monitoring & identifying progress/deterioration	The ability to monitor day-to-day and long-term changes in your physical and overall wellbeing, for yourself, and by your healthcare professionals (e.g., abdominal pain, diarrhea, fatigue) and adjustments to treatment and care based on this.
9	Access to other treatments/services (including a care coordinator), to support physical health, mental health, overall wellbeing (holistic approach)	A care coordinator, who is assigned to you, to help guide you through the healthcare system and offer emotional support; this could be an inflammatory bowel disease nurse / inflammatory bowel disease navigator / clinical nurse specialist or social worker / peer support worker. Other allied health services could include seeing a psychologist or dietitian. Complementary treatments could include acupuncture, hypnosis, mind-body therapies, taking dietary supplement/probiotics.
10	Support for your 'support person'	Information/websites specifically for significant others (e.g., spouse, partner, parent, sibling, friend etc) and support groups where family members/friends can talk with others in similar situations.
11	Inflammatory bowel disease related costs	The overall impact that having inflammatory bowel disease has on your financial wellbeing, e.g., how much you are out-of-pocket, and the impact of loss of income.

The MTM were systematically divided into 11 sets of 6 according to an experimental design, resulting in a BWS exercise containing 11 scenarios. For each scenario, participants were asked to consider the 6 displayed MTM (i.e., participants were shown 6 of the 11 MTM at any one time) and select the best and worst MTM across two dimensions: satisfaction and importance.

An example of a scenario is shown in Figure 1 below. Data collected detailed how important each MTM was to an individual, as well as how satisfied they were with each MTM.



Most satisfied	Least Satisfied		Most important	Least important
○	○	Treatment logistics	○	○
○	○	Time of diagnosis	○	○
○	○	Your involvement in decision making	○	○
○	○	Access to, and effectiveness of, medication and treatment	○	○
○	○	The quality of information available about your condition and care	○	○
○	○	Monitoring & identifying progress / deterioration	○	○

Figure 1. Screenshot of the BWS task

The BWS exercise yielded scores reflecting the relative hierarchy of each MTM vs another MTM. The **BWS scores** were calculated for each MTM by subtracting the number of times it was chosen as worst (least satisfied/important) from the number of times it was chosen as best (most satisfied/important), divided by the number of times it was shown throughout the task.

Furthermore, the BWS scores are mapped onto a scale ranging from 0 (“Not satisfied at all”/”Not important at all”) to 10 (“Completely satisfied”/”Extremely important”) describing the level of satisfaction and importance. These **rescaled scores** allow direct inference of how satisfied/important each individual MTM is, rather than just their relative ranking.

Best-Worst Scaling (BWS) scores range from -1 to 1 and represent the relative ranking (ordering) of the MTM.

- A **negative** score indicates the MTM was chosen as ***worst* more often than *best***
- A **positive** score indicates the MTM was chosen as ***best* more often than *worst***
- A **zero** score indicates the MTM was chosen as ***best* and *worst* an equal number of times** OR was **never chosen**.

Rescaled scores range from 0 to 10 and represent the individual **level of satisfaction and importance** experienced. The scale was labelled at each extreme as follows:

- 0 = “Not satisfied at all”/”Not important at all”
- 10 = “Completely satisfied”/”Extremely important”

Patient Experience Index (PEI)

Standard BWS scores cannot be used to build an index that is comparable between groups of participants because the scores represent a relative ranking. CaPPRe have developed a new method to convert these scores from relative to absolute measures which can be combined to form an index (PEI). An index was built to measure the overall satisfaction of the health experience for the treatment of IBD in ANZ. The PEI is a combined score of the 11 MTM, accounting for both satisfaction and importance, and ranges from 0 to 100.

Reasons for Dissatisfaction and Recommended Improvements

Following the BWS task, patients were asked about their reasons for dissatisfaction and for recommended improvements, for their **top 4 most important** but **least satisfied MTM**. They are presented with a choice of 'Friction points' (FP) and are asked to select the ones that are applicable to their experiences of treatment and care. Participants are then asked to expand on this in open text, and to share ideas for improvement.

The findings

Demographic characteristics

Table 2. Basic demographic characteristics of patients

Demographic characteristic	Patient (N=45)[2]
	N (%)
Gender	
Male	14 (31.1)

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[2] Abbreviations: N – sample size

Female	31 (68.9)
Age	
18-30	9 (20)
31-40	15 (33.3)
41-50	9 (20)
51-60	6 (13.3)
61-70	4 (8.9)
71-80	2 (4.4)
Occupational status	
Working (full-time)	15 (33.3)
Working (part-time)	13 (28.9)
Working (casual)	3 (6.7)
Not working	4 (8.9)
Home duties and/or caring responsibilities	1 (2.2)
Retired	7 (15.6)
Other	2 (4.4)
Ethnicity	
Australian	39 (86.7)
New Zealander	1 (2.2)
Māori	2 (4.4)
Pacific Islander	1 (2.2)
European	2 (4.4)
Location	
Metro/city	28 (62.2)
Regional	14 (31.1)
Rural	3 (6.7)

Treatment characteristics

Treatment profiles for patients are shown in Table 3. Most patients were taking medication to treat IBD at the time the study was conducted (86.7%), all others reported taking medication for IBD but have in the past (13.3%). Just over half of those currently taking regular medication to treat IBD reported taking their medication daily (51.1%), less than 20% reported taking medication weekly (17.9%), monthly (12.8%) or once every two months (10.3%).

Nearly half of the patients reported that the frequency with which they take medication impacts their quality of life (QoL) (48.7%). Most patients report forgetting to take their medication either ‘once or twice’ or ‘a number of times’ (46.2% and 20.5% respectively).

Table 3. Basic treatment characteristics

Treatment characteristic	N (%)
Treatment experience (N=45) *Question: ‘Are you currently taking, or have you ever taken medication for IBD?’*	
Currently taking medication to treat IBD	39 (86.7)
Not currently taking medication for IBD but have in the past	6 (13.3)
Have never taken medication to treat IBD	0 (0.0)

Treatment frequency (N=39) *Question: ‘How often do you take your regular medication?’*	
Daily	20 (51.1)
Weekly	7 (17.9)
Monthly	5 (12.8)
Once every two months	4 (10.3)
Other	3 (7.7)
Treatment impact on QoL (N=39) *Question: ‘Do you believe the frequency with which you take your medication impacts your quality of life?’*	
Yes	19 (48.7)
No	17 (43.6)
Not sure	3 (7.7)
Treatment adherence (N=39) *Question: How often do you forget to take your medication?*	
Never	12 (30.8)
I have once or twice	18 (46.2)
A number of times	8 (20.5)
Quite often	1 (2.6)
Always	0 (0.0)

Characteristics of Care

Treatment setting

The number of participants treated in exclusively public or private settings was even (29%). Just over 40% reported having been treated in a combination of public/private settings (42%).

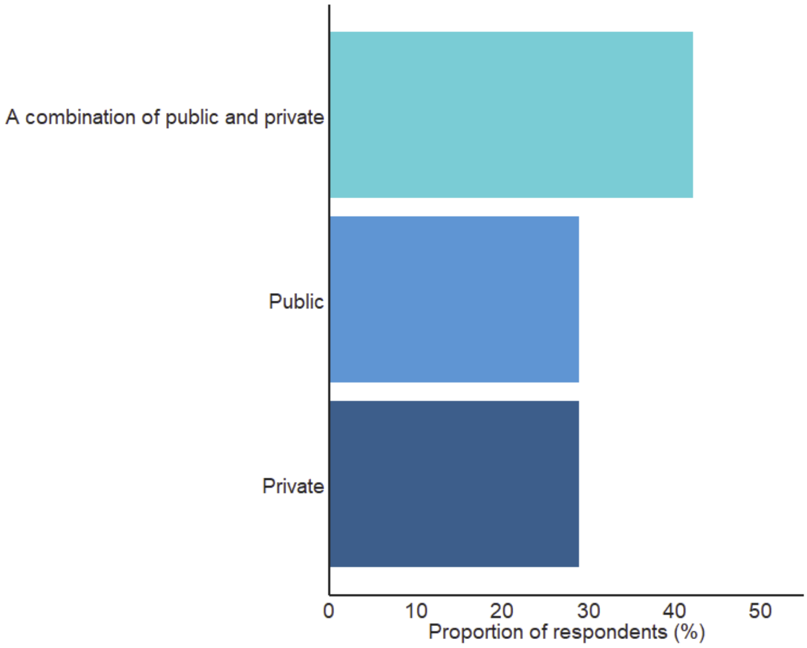

Figure 2. Treatment setting

Treatment and care costs

The greatest out-of-pocket cost to patients was private healthcare cover, with a mean of A$2,223 annually. This was followed by 'cost of medication' and 'costs of complementary treatments' with an average annual amount of A$1,803 and A$1,338, respectively.

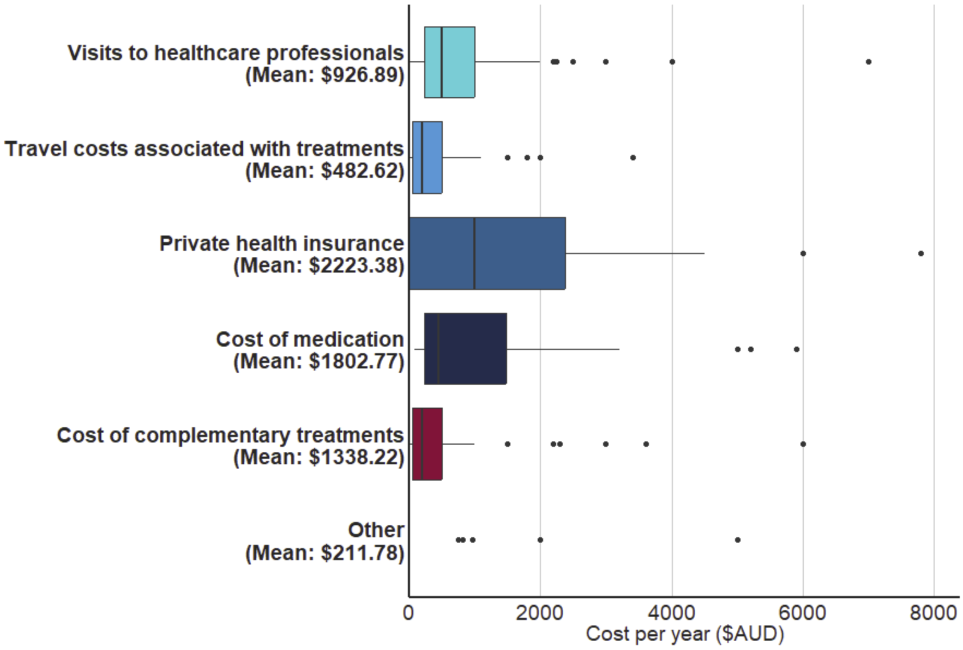

Figure 3. Treatment and care costs

Services Experienced

Nearly two-thirds of participants have made use of mainstream medical services e.g., treatment/prescription/appointment reminders (62%) and 40% were supported by patient advocacy groups. 13% of participants have a care coordinator.

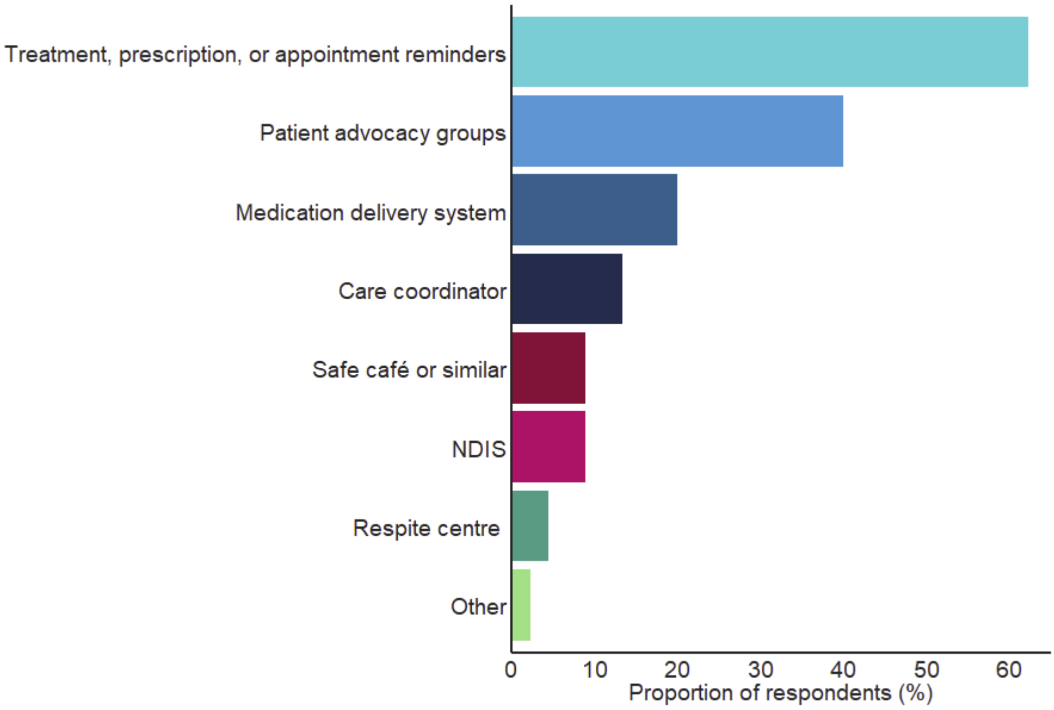

Figure 4. Services experienced

Importance & Satisfaction

PEI: patients

The PEI for patients with IBD, a measure of overall satisfaction, that accounts for the relative importance of each aspect of the healthcare pathway, is displayed in Table 4. The overall median PEI score was 54.22.

Future research could use the PEI to assess shifts in satisfaction and importance ratings, especially if programs are implemented to address specific patient groups. Please see the IBD PEI dashboard (link on page 16) for subgroups scores, e.g., by basic demographics.

Table 4. Patient Experience Index score

	Mean	Median	Std. deviation
Patient Experience Index (N=45)	56.80	54.22	13.82

Importance and satisfaction quadrant

The drivers of PEI can be examined more closely in the “quadrant map” that plots the BWS importance scores against the BWS satisfaction scores for each MTM. This acts as a visual aid in comparing how patients prioritise/rank the 11 MTM in terms of satisfaction and importance simultaneously. Figure 5 shows the quadrant map for patients. MTM located further towards the right along the x-axis represent higher satisfaction relative to the other MTM, and MTM higher up along the y-axis represent higher importance relative to the other MTM. MTM in the upper left quadrant are rated high on importance but low on satisfaction.

‘Access to other treatments/services’, ‘IBD related costs’, and ‘Support person support’ had negative satisfaction scores, but their importance scores were also negative, indicating lower priority. On the other hand, ‘Access to, and effectiveness of, medication’, ‘Healthcare team quality’, ‘Monitoring and identifying progress/deterioration’ and ‘Information quality’ had positive important scores, their satisfaction scores were also positive, i.e., they were greater than 0, indicating that patients are, overall, satisfied with these high priority MTMs. However, it is important to note that the positive levels of satisfaction for these MTM are not high and therefore these MTM may still represent priority areas for improvement upon reviewing the findings as a whole.

‘Side effects of medication and treatment’ had a negative satisfaction and a positive importance score, placing the MTM in the upper left quadrant, indicating improvements in satisfaction in this MTMs may result in considerable improvements in overall satisfaction.

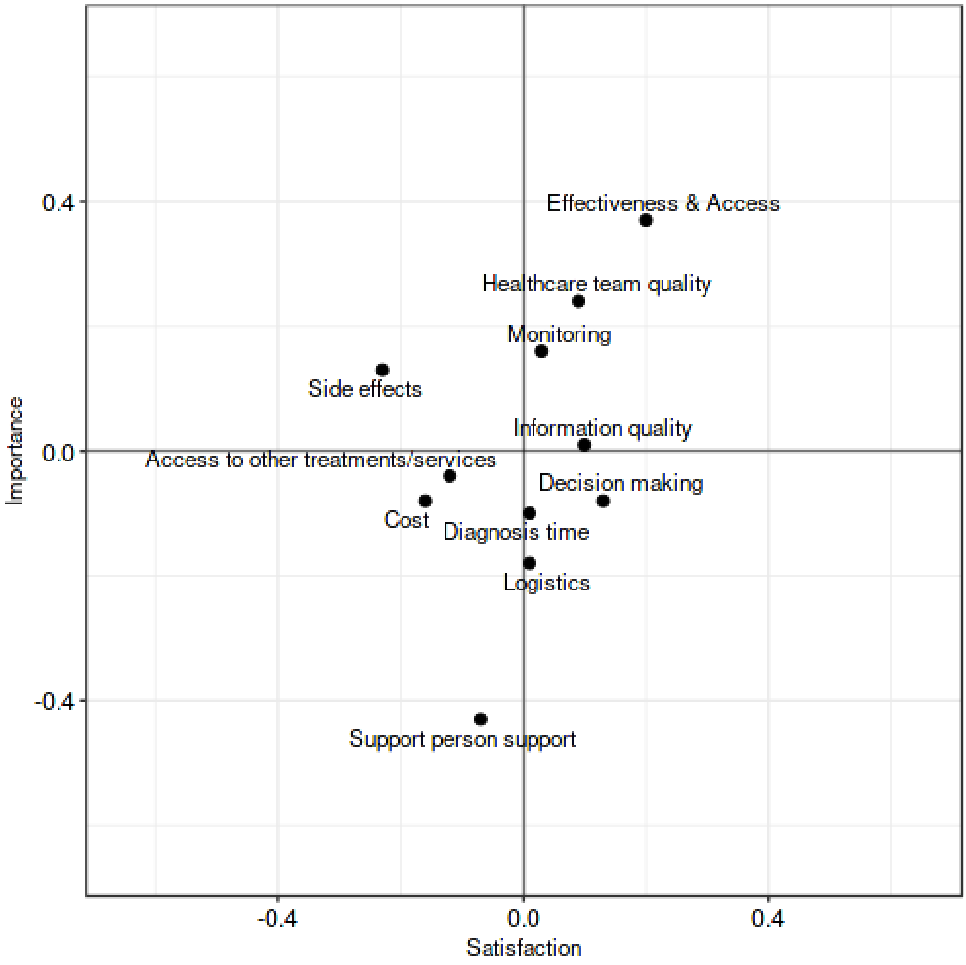

Figure 5. BWS quadrant map

Rescaled importance and satisfaction

Figure 6 displays the rescaled importance and satisfaction scores. The rescaled values directly correspond to the level of satisfaction and importance stated between “Not satisfied at all”/”Not important at all” (0) and “Completely satisfied"/"Extremely important" (10). The magnitude of the satisfaction and importance can be compared to identify differences between the level of satisfaction and importance of each MTM. The MTM have been ordered from top to bottom by importance level, i.e., the most important MTM appears at the top of the figure.

Two MTM, 'Access to, and effectiveness of, medication' (7.72) and 'Healthcare team quality' (7.22) appear to be especially important, on average. 'Support person support' (4.24), 'Treatment logistics' (5.50) and 'IBD related costs' (5.65) appeared to be the least important, on average.

Patients were least satisfied with 'Side effects of medication and treatment' (4.79), 'IBD related costs' (5.23) and 'Support person support' (5.37) following close behind.

Satisfaction levels were lower than importance levels for most MTM (8 out of 11). The largest gaps between importance and satisfaction were found in 'Side effects of medication and treatment', 'Access to, and effectiveness of, medication' and 'Healthcare team quality'[3].

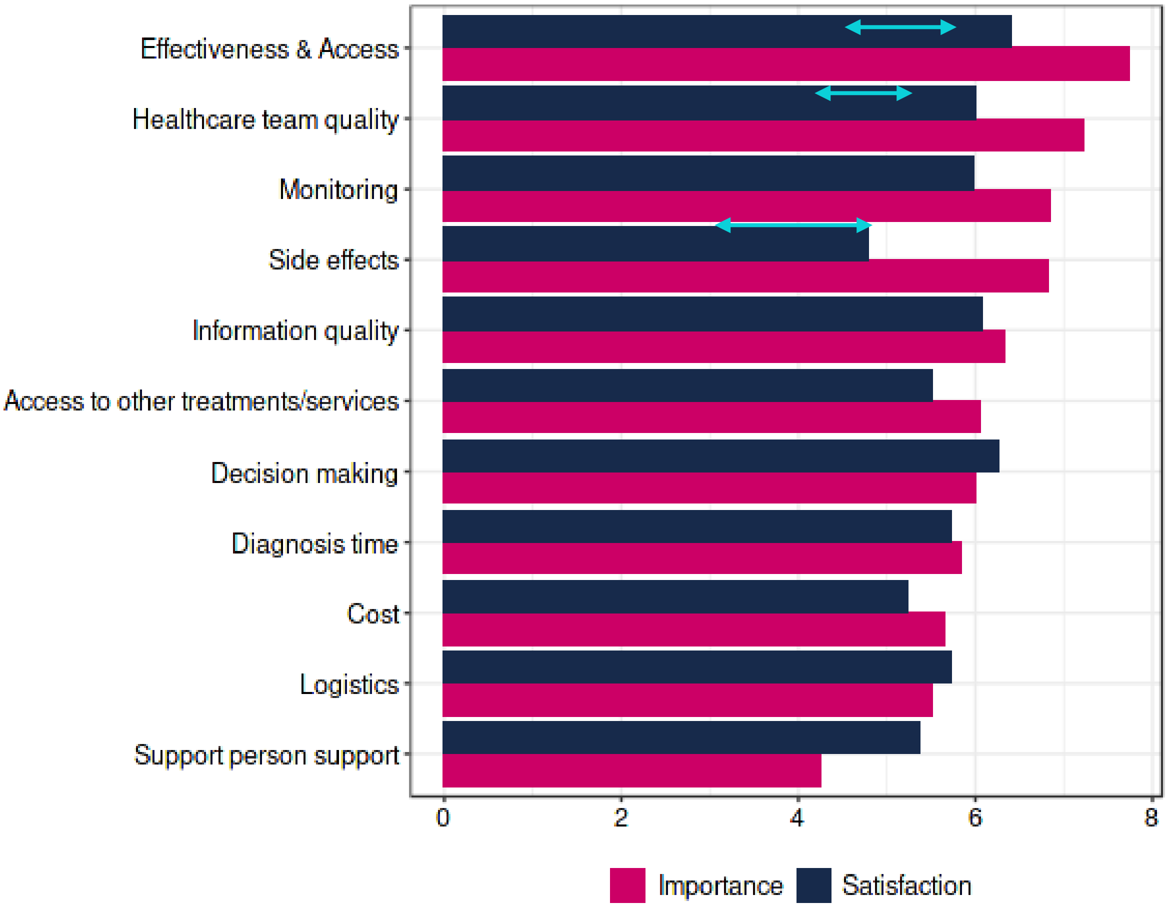

Figure 6. Rescaled importance and satisfaction

Top 4 Least Satisfied / Most important

Figure 7 illustrates the MTM that were most important to patients, however for which they were least satisfied, combining the top 4 of each most important/least satisfied MTM for each participant; 'Side effects of medication

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[3] 'Access to, and effectiveness of, medication' and 'Healthcare team quality' had positive satisfaction and importance scores and therefore sat at the top right quadrant of the quadrant plot, indicating that patients were overall satisfied in these high priority areas (Figure 5). However, the satisfaction scores were still low relative to the importance scores, creating a large gap between satisfaction and importance for the two MTM.

It is important that all findings are reviewed together when identifying the key areas for improvement.

and treatment', 'Access to, and effectiveness of, medication', 'Healthcare team quality' and 'Monitoring and identifying progress/deterioration' came out top and are indicative of priority areas for improvement.

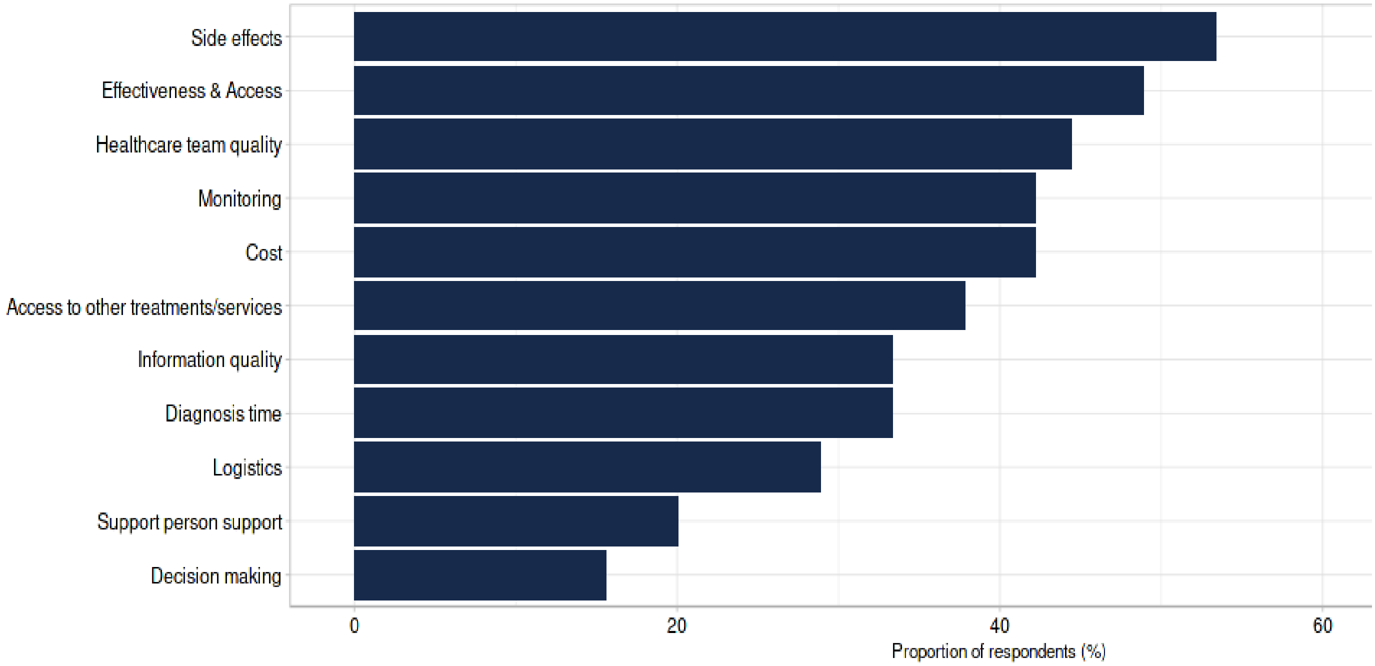

Figure 7. Top 4 least satisfied and most important MTM

Conclusion

Findings from this research suggest a mix of medication and healthcare MTM could be targeted to increase patient satisfaction, particularly if the areas targeted for change are also those which patients consider to be most important within the treatment and healthcare pathway.

Potential MTM to target

Least satisfied/most important

- Side effects of medication and treatment
- Access to, and effectiveness of, medication
- Healthcare team quality
- Monitoring & identifying progress/deterioration

Biggest gaps between satisfaction and importance

- Side effects of medication and treatment
- Access to, and effectiveness of, medication
- Healthcare team quality

Patient ideas on what could be done to improve these areas of dissatisfaction:

Side effects of medication and treatment

An overarching theme for the MTM was dissatisfaction around the impact of side-effects from medication and treatment on day-to-day life (e.g., impact on mental and/or physical health). Two patients reported having to change their career, reduce study, and have missed out on time with friends and family due to side effects associated with their medication and/or treatment; another patient reported experiencing a severe decline in mental health after starting IBD medication.

Patients asked for more guidance and support from their healthcare professionals on the management of treatment side effects, and for more information to be provided on the variety and severity of potential side effects. Patients commented on the need for more research and investment into the development of new accessible medication with fewer side effects.

Access to, and effectiveness of, medication

Eleven patients were not satisfied with how well their medication / treatment works to prevent further symptoms associated with IBD (e.g., abdominal pain, diarrhea, fatigue, body aches, frequent need/urge to urinate, rectal bleeding). Two patients commented on having a poor quality of life despite being on medication, leading them to feel ‘hopeless and frustrated’.

Four patients asked for more guidance and information regarding IBD clinical trials, as many were unaware of any. A few called for more tailored medication/treatment choices, and patients suggested their healthcare professionals spend more time listening to their thoughts and opinions on medication.

Healthcare team quality

Six patients were dissatisfied with the communication from their healthcare professionals outside of consultations; one patient reported having to push for a response after trying to obtain support regarding their side effects. Three patients expressed dissatisfaction over difficulties contacting their healthcare professionals or nurses at short notice and/or after hours. Patients called for a '24-hour care' system, either via phone or email.

There was some dissatisfaction around the lack of empathy provided by healthcare professionals towards patients; patients mentioned that their healthcare professionals lacked interest in their needs, feelings and emotions. Patients asked for more support and a genuine desire from their healthcare professionals to listen.

Five patients were unhappy with the lack of integration and communication within their healthcare team and suggested the need for more systemic coordination. Patients suggested healthcare professionals make more use of apps such as 'My Health Record' in order to log patient records in one place – and also to improve efficiency for record sharing within the healthcare team and with patients.

Monitoring & identifying progress/deterioration

Patients commented on the lack of tools to help them track/monitor changes; three patients reported that they were not aware of any tools used for monitoring/tracking changes in their physical and mental health (including their overall wellbeing), and they would like a health records system that would highlight these changes over time (i.e., an app).

Four patients expressed dissatisfaction over long wait times for testing (e.g., blood tests and/or getting an appointment with their doctor) when experiencing symptom change, where one patient suggested referrals for tests be more accessible.