

## PATIENT SURVEY DATA

The patient survey data was designed to collect data around the patient experience of Crohn's disease, particularly in respect to the early stages of the care pathway that were difficult to capture in the case-review. The survey was designed with the help of the patient participation group and the study advisory group, who commented on the content and wording of the survey questions. Survey participants were aged 16 years or older and had all been diagnosed with Crohn's disease and undergone surgery for their condition.

The survey was created and disseminated in Qualtrics© and was open over a 6-month period (June - December 2022) and was promoted with the help of Crohn's & Colitis UK and IBD-UK. In total 319 surveys were completed.

### Who completed the survey?

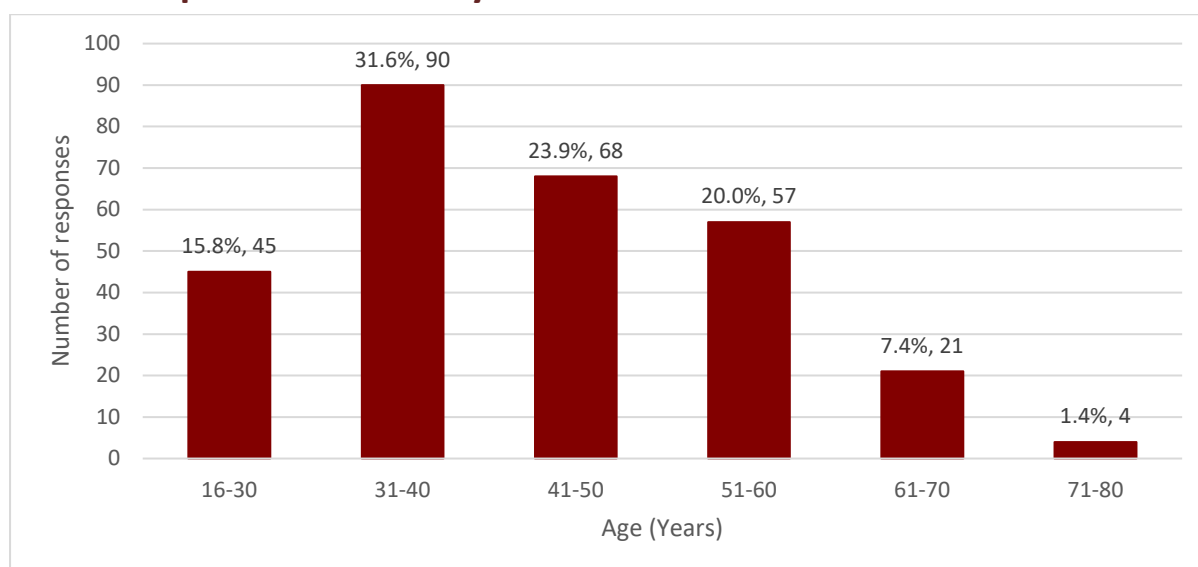


Figure 1: Patient survey data: n=285

Table 1: Sex

Sex	Number of respondents	%
Female	238	74.6
Male	79	24.8
Non-binary	2	0.6
<b>Total</b>	<b>319</b>	

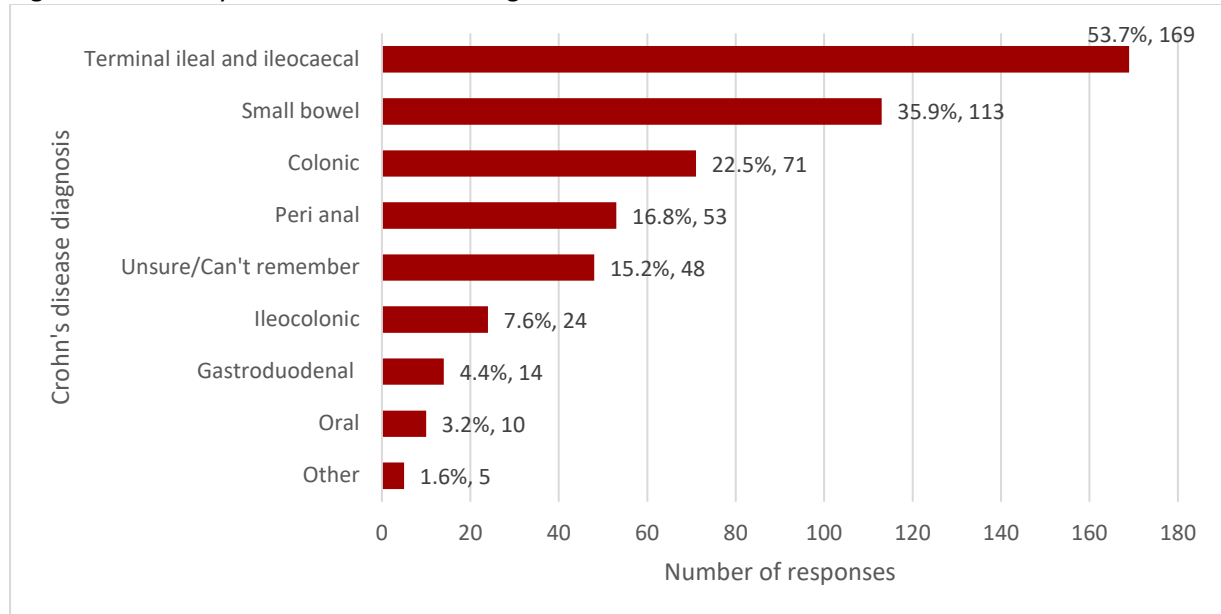
Patient survey data

There were some differences between the survey population and patients selected for the case review in terms of demographics. The survey population had 135/285 (47.4%) patients under the age of 40 compared to 314/553 (56.8%) as identified in the Clinician Questionnaire from the main study. However, the patient survey population had a much higher proportion of female patients with three quarters of the population 239/319 (74.6%) being female compared with a more even split in the case study population (250/553; 45.2%).

## Crohn's disease diagnosis

We asked the patients in the survey to report on the site/sites of their Crohn's disease. The most frequent was "terminal ileal and ileocaecal" representing 169/315 (53.7%) of the sample.

Figure 2: What is your Crohn's disease diagnosis?



Answers may be multiple, Patient survey data n=315

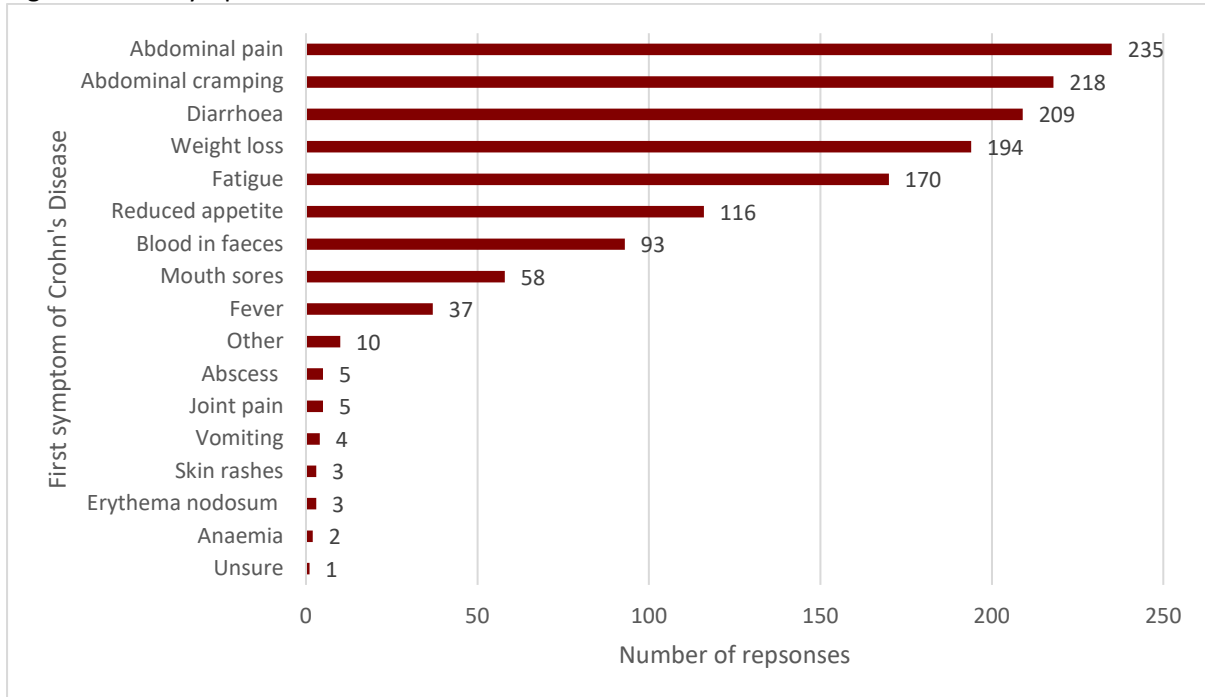
Figure 3: How long ago were you diagnosed with Crohn's disease?



Patient survey data, n=314

Nearly 70% (216/314; 68.7%) of respondents were diagnosed more than 10 years ago. This highlights the long-term nature of Crohn's disease and its lifetime impact.

Figure 4: First symptoms of Crohn’s disease?



Answers may be multiple. Patient survey data, n=317

The commonest first symptoms of Crohn’s disease were abdominal pain and cramps, diarrhoea and weight loss. Over 70% (215/300; 71.6%) of patients first visited their GP within 6 months of their first symptoms. It took a further 6 months for a diagnosis of Crohn’s disease to be made in 70.0%; 218/311 of respondents. The diagnosis was made by a gastroenterologist in the vast majority (226/279; 50.8%). Once diagnosed, most respondents (95/131; 72.5%) were seen by the IBD team within 6 weeks.

Table 2: Time between first symptoms and first visit to healthcare professionals

How long between first symptoms and first visit to healthcare professional	Number of responses	%
Less than 4 weeks	68	22.7
1 - 3 months	88	29.3
4 - 6 months	59	19.7
7 - 12 months	28	9.3
1 - 2 years	34	11.3
2 - 5 years	7	2.3
More than 5 years	16	5.3
<b>Subtotal</b>	<b>300</b>	
Unsure	16	
<b>Total</b>	<b>316</b>	

Patient survey data, n=316

Table 3: Time between first symptoms and receiving a formal Crohn's disease diagnosis

How long between first symptoms and receiving a formal Crohn's disease diagnosis	Number of responses	%
Less than 4 weeks	7	2.3
1 - 3 months	38	12.2
4 - 6 months	48	15.4
7 - 12 months	60	19.3
1 - 2 years	74	23.8
2 - 5 years	45	14.5
More than 5 years	39	12.5
<b>Subtotal</b>	<b>311</b>	
Unknown	4	
<b>Total</b>	<b>315</b>	

Patient survey data, n=315

Table 4: Which healthcare professionals confirmed Crohn's disease diagnosis?

Which healthcare professional confirmed your diagnosis of Crohn's disease?	Number of responses	%
Gastroenterologist	226	81.0
Colorectal Surgeon	56	20.1
A&E Doctors	12	4.3
IBD Nurse specialist	8	2.9
GP	6	2.2
Paediatric doctor	4	1.4
Other - Please specify	4	1.4
General surgeon	3	1.1
Gynaecologist	2	0.7
Other nurse	2	0.7
<b>Subtotal</b>	<b>279</b>	
Unsure/ Can't remember	5	
<b>Total</b>	<b>304</b>	

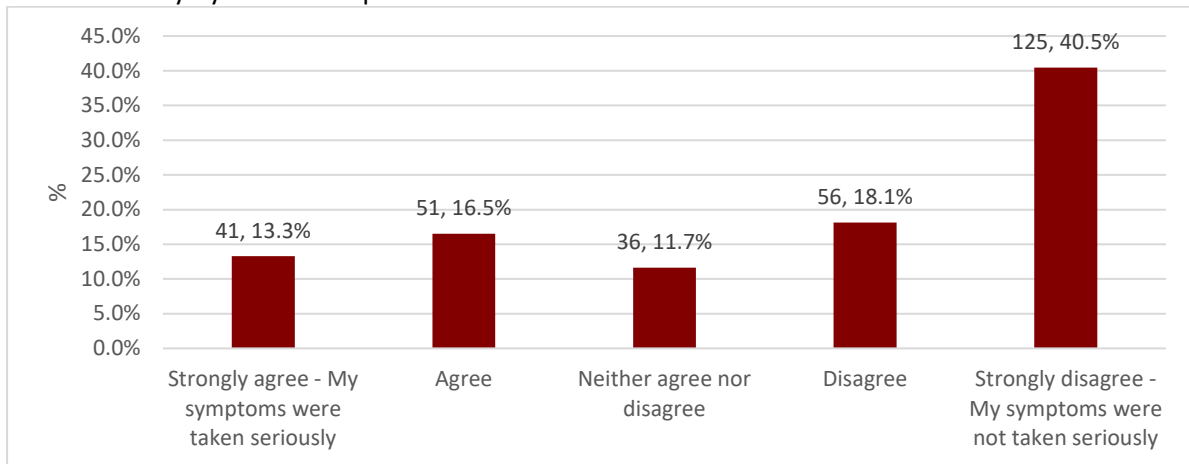
Patient survey data, n=304

Table 5: How long did you wait for an IBD team appointment?

IBD team appointment wait time	Number of responses	%
Less than 4 weeks	61	46.6
4 - 6 weeks	34	26.0
6 - 8 weeks	12	9.2
8 - 12 weeks	14	10.7
12+ weeks -please specify	10	7.6
<b>Subtotal</b>	<b>131</b>	
Unsure	58	
<b>Total</b>	<b>189</b>	

Patient survey data, n=189

Figure 5: Before being formally diagnosed with Crohn's disease, do you think your symptoms were taken seriously by healthcare professionals?



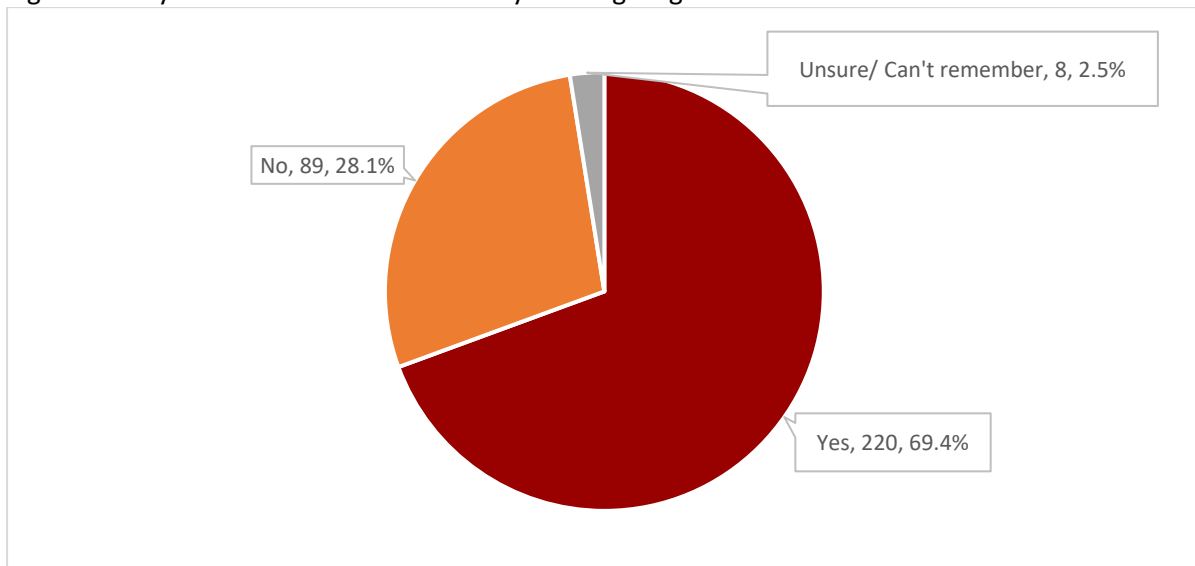
Patient survey data, n=309

Prior to diagnosis, many patients (181/309; 58.6%) did not feel that their symptoms were taken seriously by healthcare professionals and (220/317; 69.4%) felt that there was a delay in diagnosis of their condition.

*“My GP was very direct and told me I had either Bowel Cancer or Colitis (turned out to be Crohn's) Although a shock, his response was incredible. I was sent straight to Gastro for scopes and further investigations.”*

*“GP was reluctant to refer me to gastroenterologist. Frequent visits to A&E with no follow up or tests.”*

Figure 6: Do you feel that there was a delay in being diagnosed with Crohn's disease?



Patient survey data, n=317

Table 6: Please select all the information that you were given when you were first diagnosed with Crohn's disease:

Information given when first diagnosed with Crohn's disease	Number of responses	%
Written information sheet/ booklet	154	48.9
Information of specific website address e.g Crohn's & Colitis UK	120	38.1
Information was mentioned in conversation	119	37.8
Specific contact details of IBD helpline	100	31.7
Information about local peer support groups	58	18.4
Information about what to expect about disease progression	53	16.8
Information about what to do upon a flare	49	15.6
None	43	13.7
Unsure	32	10.2
Other - Please specify	20	6.3
<b>Total</b>	<b>315</b>	

Answers may be multiple; Patient survey data, n = 315

The majority of patients surveyed were given some form of information about their condition at the time of diagnosis (240/315; 76.1%). However, it was not comprehensive, and 163/271 (59.1%) felt that they were not given sufficient information.

*"I don't remember being made aware about support groups when I was diagnosed and felt very isolated due to that."*

*"I had to research myself. I was scared. I had never heard of Crohn's disease. Crohns and Colitis UK gave me hope and information."*

Table 7: Do you feel that you were given sufficient information about Crohn's disease when you were first diagnosed?

Do you feel that you were given sufficient information about Crohn's disease when you were first diagnosed?	Number of responses	%
Yes	108	39.9
No	163	59.1
<b>Subtotal</b>	<b>271</b>	
Unsure/ Can't remember	45	
<b>Total</b>	<b>316</b>	

Patient survey data, n=316

Most respondents (192/303; 63.4%) reported that they that they were referred to an IBD team at diagnosis.

Table 8: When you were first diagnosed with Crohn's disease, were you referred to an IBD team?

IBD team referral at diagnosis	Number of responses	%
Yes	192	63.4
No	111	36.6
<b>Subtotal</b>	<b>303</b>	
Unsure	10	
<b>Total</b>	<b>313</b>	

Patient survey data, n=313

## Crohn's disease flare

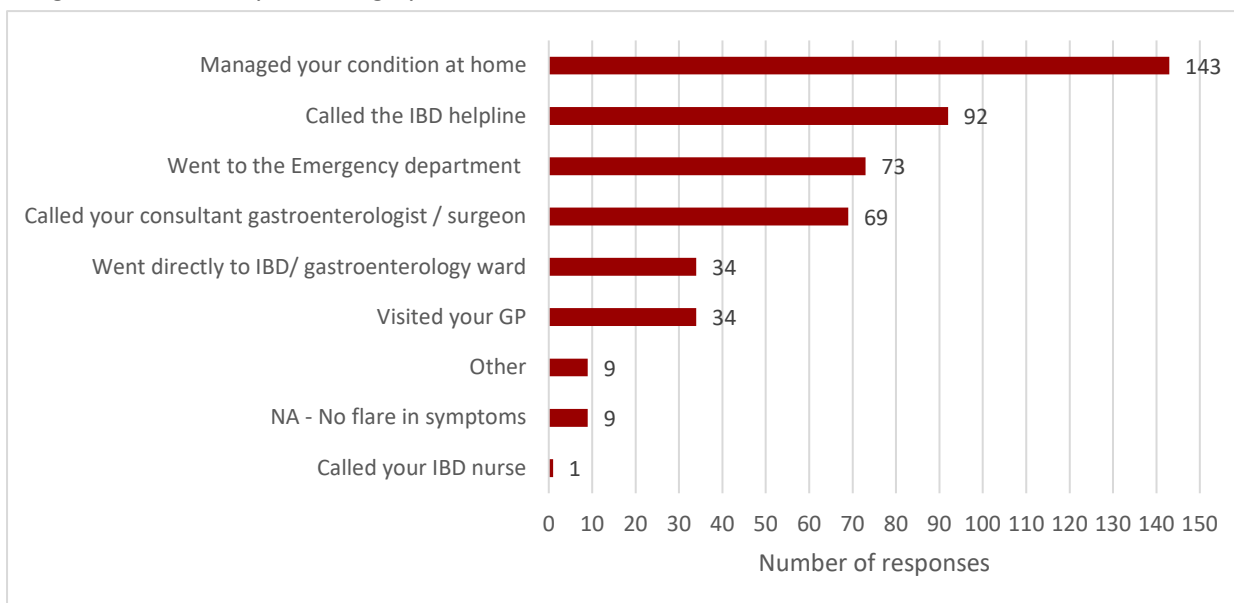
A flare describes when symptoms worsen and can be defined in some of the following ways: a change in toilet habits, blood in poo, abdominal pain. Flares aren't always just in the gut and can also include other inflammatory symptoms outside the bowel e.g. mouth ulcers, joint pain, skin rashes etc. Over half (61.1%; 156/255) of the patients responding to the survey had experienced a flare in their symptoms within the past 2 years, which included the period of the COVID-19 pandemic. Possibly due to this timeframe, when it was less possible to visit the GP or emergency department, most respondents managed their condition at home. Just over a third of patients (92/255; 36.1%) called the IBD helpline. The majority (173/276; 63.0%) were satisfied with the advice/ care they received.

Table 9: When was your last Crohn's disease flare in symptoms?

Last Crohn's disease flare	Number of responses	%
Flare in 2022	126	49.4
Flare in 2021	30	11.8
Flare in 2020	21	8.2
Flare between 2010-2019	69	27.1
Flare between 2009 - 2001	5	2.0
Flare before 2000	4	1.6
<b>Total</b>	<b>255</b>	

Patient survey data; n = 255

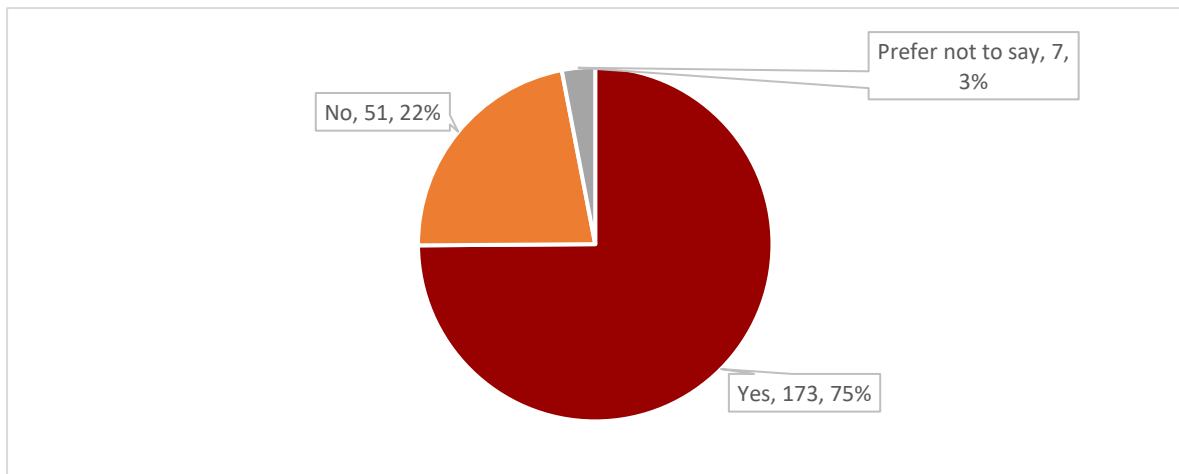
Figure 7: How did you manage your last Crohn's disease flare?



Answers may be multiple; Patient survey data; n = 277

Of the respondents who had a flare and sought advice, almost three-quarters (173/231; 72.6%) reported being satisfied with the care/ advice they received.

Figure 8: Were you satisfied with the care/ advice you received during your flare?



*Patient survey data, n=231*

Of those patients who were dissatisfied with the advice they received; the main reason given was difficulty in accessing the IBD team.



## Crohn's disease surgery

Approximately a third (99/298; 33.2%) of respondents had had their surgery for Crohn's disease between 2020 – 2022.

Table 10: When did you have your most recent surgery for Crohn's disease?

Most recent Crohn's surgery	Number of responses	%
Surgery in 2022	47	15.8
Surgery in 2021	30	10.1
Surgery in 2020	22	7.4
Surgery between 2010-2019	144	48.3
Flare between 2009 - 2000	33	11.1
Flare before 1999	18	6.0
<b>Total</b>	<b>298</b>	

Patient survey data, n = 298

A planned elective procedure for Crohn's disease was reported in 163/309 (52.8%) of respondents. Notably 40/309 (12.9%) of respondents had a planned procedure that became an emergency, as emergency procedures tend to have poorer outcomes. The NCEPOD study identified 25 patients who presented as an emergency who were already on a waiting list for an elective operation.

Table 11: Was the surgery you had for Crohn's disease:

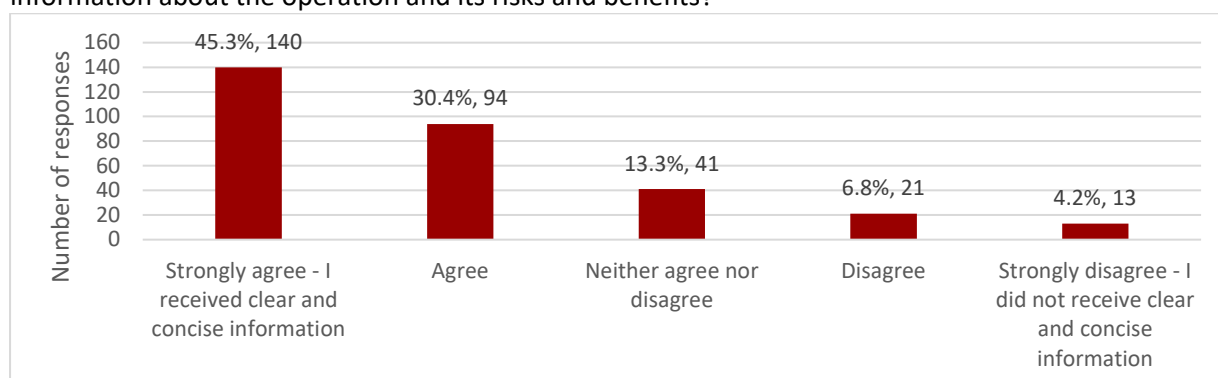
Type of surgery	Number of responses	%
A planned elective procedure	163	52.8
A planned procedure that became an emergency	40	12.9
An emergency procedure	106	34.3
<b>Subtotal</b>	<b>309</b>	
Unsure	5	
<b>Total</b>	<b>314</b>	

Patient survey data, n= 314

*"I was on a waiting list for procedure and ended up with a bowel obstruction so had to have emergency surgery."*

Many respondents (234/309; 75.7%) who underwent surgery felt that they received clear and concise information relating to the operation's risks and benefits.

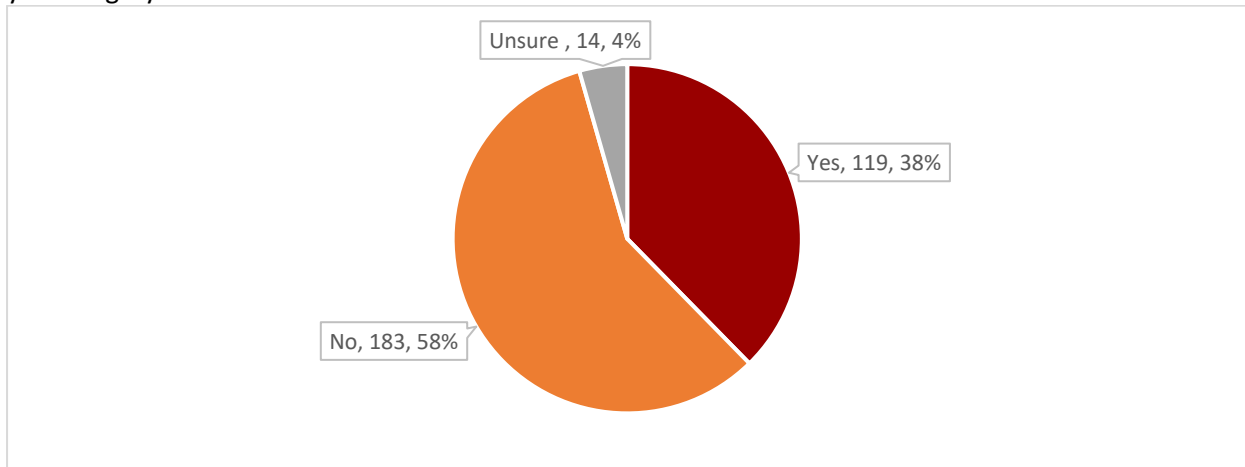
Figure 9: Prior to your most recent surgery, do you feel that you received clear and concise information about the operation and its risks and benefits?



Patient survey data, n=309

Only 119/316; 37.7% respondents felt that there had been a delay in having their surgery. Most patients cited the Covid-19 pandemic as the reason for the delay in their surgery.

Figure 10: Thinking back to your most recent surgery, do you feel that there was a delay in having your surgery?



Patient survey data, n=316

7 out of 10 respondents were happy with the care and support they received from the healthcare team after surgery. 48/84 respondents would have liked to have been provided mental health support after surgery, with 34/48 respondents thought pain service advice could have been improved.

Table 12: Were you happy with the amount of care and support you received from your healthcare team after surgery?

Happy with care and support post-surgery	Number of responses	%
Yes	210	70.9
No	86	29.1
<b>Subtotal</b>	<b>296</b>	
Unsure	19	
<b>Total</b>	<b>315</b>	

Patient survey data

154/305 (50.5%) respondents' self-reported having complications after surgery, with 76/154 reporting infections as their complication – this ranged from wound infections to sepsis.

Table 13: Did you have any complications/ problems after your surgery?

Complications post-surgery	Number of responses	%
Yes	154	50.5
No	151	49.5
<b>Subtotal</b>	<b>305</b>	
Unsure	11	
<b>Total</b>	<b>316</b>	

Patient survey data

When asked if they were happy with the amount of care and support, they received from the healthcare team after experiencing complications post-surgery, two-thirds of respondents (95/141; 67.4%) said “Yes.”

Table 14: Were you happy with the amount of care and support you received from your healthcare team after experiencing complications/ problems post-surgery?

Care and support for complications post-surgery	Number of responses	%
Yes	95	67.4
No	46	32.6
<b>Subtotal</b>	<b>141</b>	
Unsure	13	
<b>Total</b>	<b>154</b>	

*Patient survey data*

*“Need to be listened to and follow up appointments booked, especially when newly diagnosed as it is a big change to your life coming to terms with a long-term medical condition.”*

*“To be listened to by surgeon. To be given consistent care. To be given consistent plan for care that was followed. Honest regular communication.”*

## Crohn's disease medication

Almost two thirds of respondents (207/315; 65.7%) were taking medications to manage their Crohn's disease.

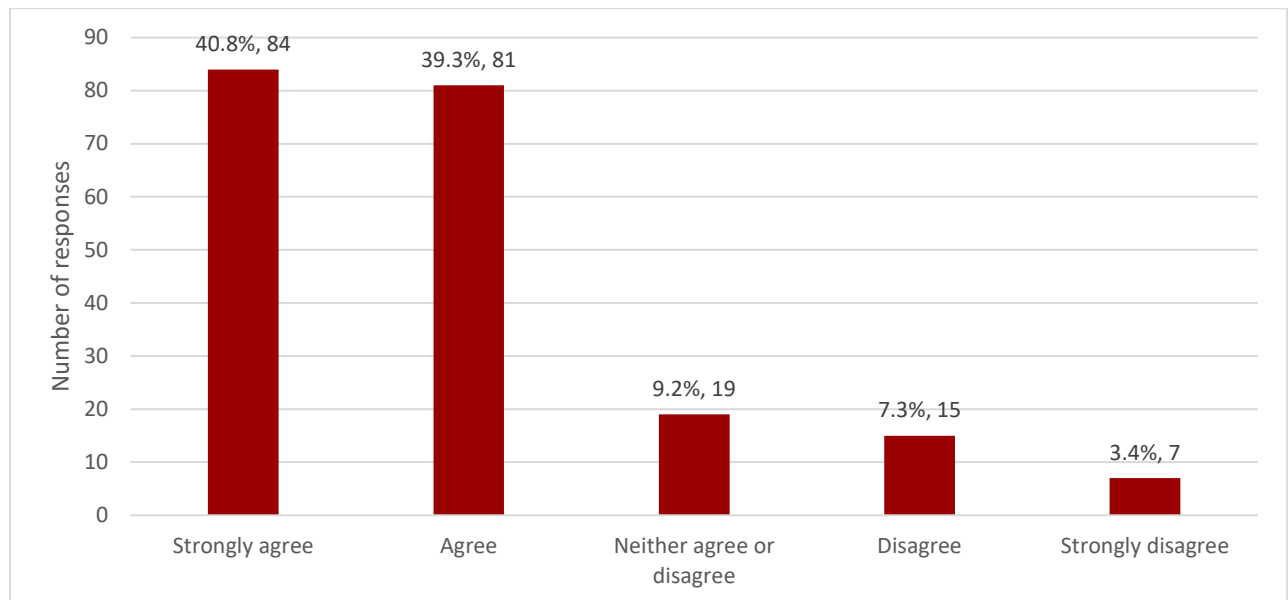
Table 15: Are you currently taking medication(s) for the management of your Crohn's Disease?

Currently on medication	Number of responses	%
Yes	207	65.7
No	108	34.3
<b>Total</b>	<b>315</b>	

Patient survey data

7 in 10 participants reported that they felt they were given information and the opportunity to ask questions about their prescribed medications and any possible side effects.

Figure 11: Do you feel that you were given information and the opportunity to ask questions about your medication(s) and any possible side effects?



Patient survey data, n=206

*"Medications control symptoms well but side effects are a problem."*

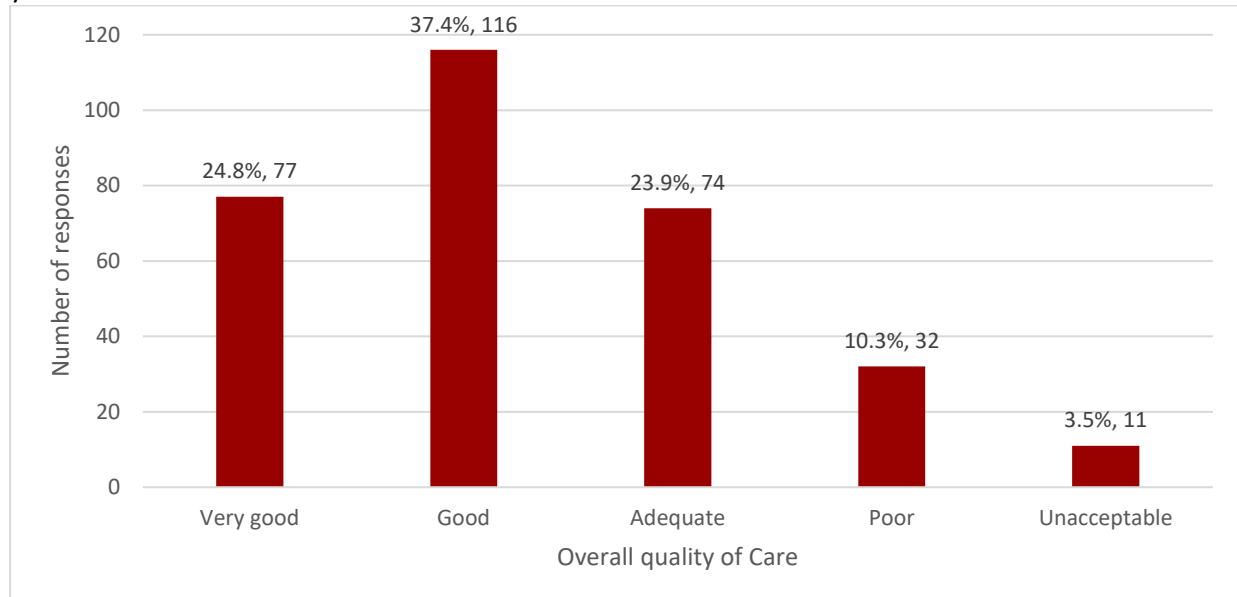
*"Frustrating. I had to go through multiple medications before finding one that is apparently working. This resulted in a huge amount of lost time while my intestines became more and more damaged."*

*"Excellent support & information for biologics treatment from my IBD nurse"*

## Overall Quality of Crohn's disease care

The patient survey respondents were also asked to rate their overall quality of care on a five-point scale (Figure 12). Taken at face value the patients rate their care reasonably highly with 63.5% (193/310) rating it as good or very good. A quarter of respondents (23.9%; 74/310) considered their care adequate and 13.9% (43/310) poor or inadequate.

Figure 12: Generally, how would you describe the quality of the healthcare you have received for your Crohn's disease care?



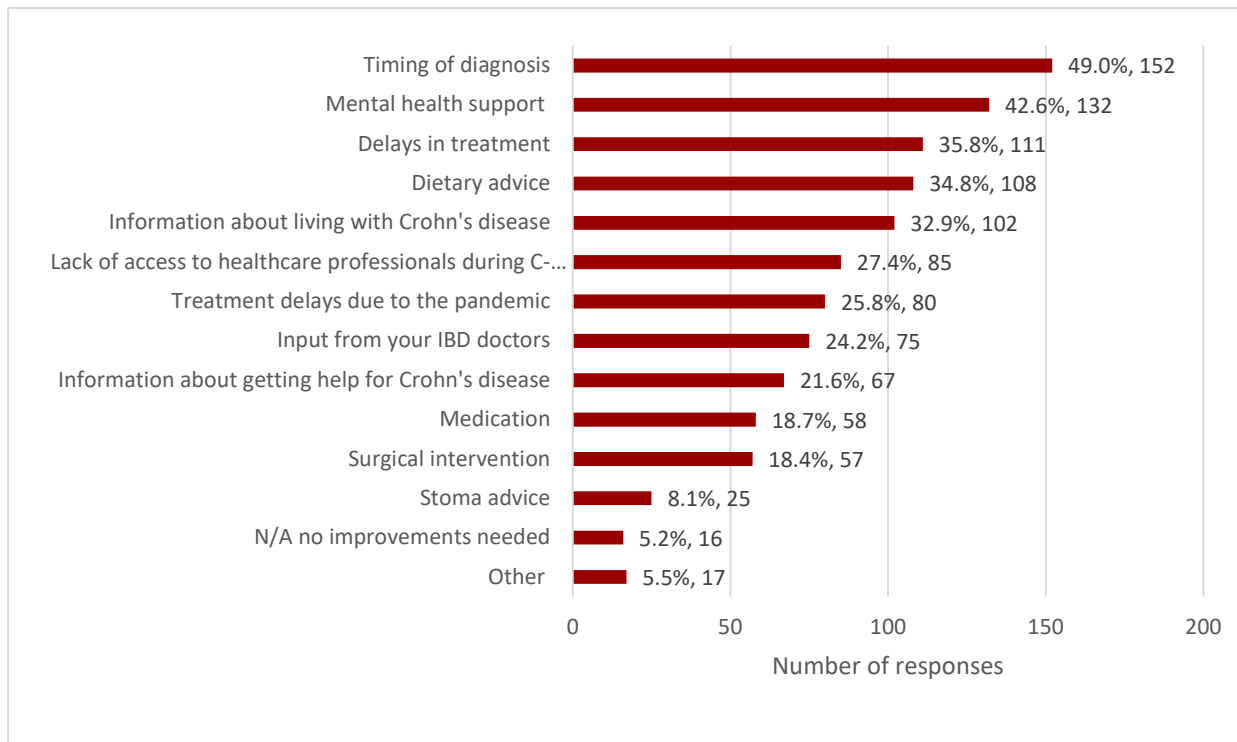
Patient survey data, n=310

The patients do not expect perfect care and were not unduly critical. A less positive picture arises when they were asked if there were any areas of their care that could be improved (Figure 13). Only 5.2% (16/310) did not highlight any areas to improve.

The commonest concern was a delay in the diagnosis of their Crohn's Disease. Half of the patients (49.0%: 152/310) experienced diagnostic delays.

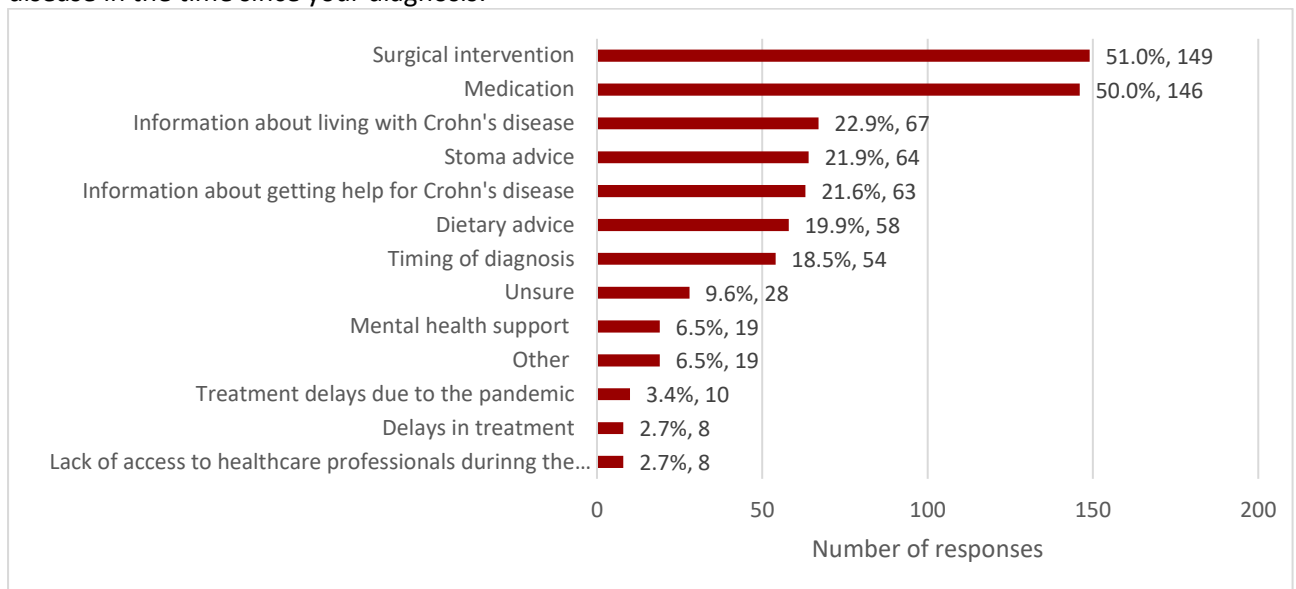
Services that the patients wanted that were not being provided were psychological support in 42.6% (132/310) and dietetic support 34.8% (108/310). Delays in their treatment was indicated by a just over a third of respondents (35.8%; 111/310). More generic support was considered important by 32.9% (102/310) respondents who wanted better information about living with Crohn's Disease and 21.6% (67/310) who considered the signposting of Crohn's Disease services could be improved. The selected cases for this study that were peer reviewed did not find a clear impact of the pandemic, but rather the same themes arose irrespective of pre or post Covid-19. The patient survey data indicated that COVID had an impact on Crohn's Disease care. 27.4% (85/310) had difficulty accessing healthcare professionals and 25.8% (80/310) had treatment delays they attributed to the impact of COVID.

Figure 13: Please list any areas where there was room for improvement in your care:



Patient survey data, n=310

Figure 14: Please select the areas that you feel went well with the management of your Crohn's disease in the time since your diagnosis:



Patient survey data, n=292

### Examples of good overall care

Aspects of care that were associated with positive evaluation of quality of care including a holistic approach being taken, regular and robust monitoring. A compassionate and caring approach and active communication with carers were also valued. Examples of good care are summarised in Table 16.

Table 16: Examples of overall care that carers and patients rated as good or very good

Examples of overall care that carers and patients rated as good or very good
<i>IBD nurses &amp; physio post-surgery are an effective route to management post-surgery. Written information and peer support is good context for new diagnosis to stop doom scrolling the internet</i>
<i>It has changed a lot since I was diagnosed, and services are a lot better. A lot of problems are NHS issues not my medical team issues. My current gastroenterologist is excellent. I cannot speak highly enough of the IBD Nursing Team especially when I started on biologics, and the Stoma Nurses during the 2 years I had a stoma. The Community Stoma Nurse was also excellent after I had my reversal and was struggling at home.</i>
<i>IBD nurses have been a great addition to patient care and all IBD patients should have access to them.</i>

Patient survey data

### Examples of less good overall care

Aspects of care that were associated with negative evaluations of quality and care are summarised in Table 17. These related to perceptions of inefficient clinical care systems, problems with staff skills, knowledge and attitudes and a range of organisational factors contributing to poor experience and gaps in care.

Table 17: Examples of less good overall care

Area of concern	Challenge identified	Example
<b>Holistic support for patients (Psychological, dietetic input etc)</b>	Lack of psychological input following surgery	<i>Mental health isn't focused on enough. Therapy should be a must after huge surgery.</i>  <i>I really needed more support with my recovery, and I wish I had been warned about the things I experienced. I still suffer from anxiety and trauma symptoms.</i>
	Lack of dietetic input	<i>Advice about diet after surgery</i>
	Lack of person-centred care	<i>Could be much better - more tailored to the individual, more information and contact, mental health support lacking but vital, GPs could be better informed. Dietary advice sadly lacking</i>
<b>Medication management</b>	Some patients Crohn's disease does not respond to drug treatment	<i>I had multiple appointments with gastroenterology and GP visits, where I tried to impress how ill I was and how little the steroids I was on were helping. While I was in remission, I felt I was forgotten about and lost to the system despite still experiencing some symptoms and needing support. That said, the IBD and stoma nurses were and are always fantastic, incredibly empathetic and good at what they do."</i>

	Inconsistent prescribing	<i>Since being on biologics I would say the experience has been positive in managing the disease but has at times come with life threatening side effects. It's a difficult situation but leaving the disease untreated would-be life threatening also</i>
<b>Decision for surgery</b>	Surgery not being considered as a potential treatment option for patients with Crohn's disease	<i>It was evident that I would need surgery, but my IBD team never referred me for a discussion with a surgeon, until one day I had a routine small bowel scan and was told to make my way to A&amp;E immediately as the situation had become so severe. I was operated on four days later.</i>
<b>Surgery Delays (falling off elective list)</b>	Surgery not being performed promptly once a decision to operate has been made	<i>Due to covid... was supposed to be on liquid diet for 6-8 weeks prior to operation - but operation got delayed so was on liquid diet for 5-6 months.</i>
		<i>The surgeon's waiting list was incredibly long, and of course there were emergency operations, which pushed me back. Waited at least 18 months and had to get the patient advisory and liaison people involved. Even then I had a short-notice cancellation.</i>
<b>Gastroenterology review/ handover/ communication</b>	Poor handover of care from the surgical team to the medical team	<i>I had emergency surgery at a hospital, which wasn't my local one and the information about my surgery wasn't passed on.</i>
		<i>Not enough psychological support. Not enough staff training. Not told about potential fertility issues. Wasn't offered to freeze my eggs and then had to pay for IVF... Thank goodness I could pay otherwise I would be childless. The CCG refused to fund it because Crohn's disease surgery isn't a good enough reason on their eyes.</i>

Patient survey data