IBD Benchmarking Tool 2019/2020
Patient Survey Report

Harrogate District Hospital

Working together for everyone affected by Inflammatory Bowel Disease
Foreword

I am delighted to be able to share with you the results from the Inflammatory Bowel Disease (IBD) Patient Survey 2019 for Harrogate District Hospital, available online at www.ibduk.org.

This is the first time that patients have had the opportunity to feedback on the quality of care they receive against the IBD Standards. The IBD Standards were published in 2019 by IBD UK, a partnership of 17 patient and professional organisations working together for everyone affected by IBD. The survey asked people with Crohn's or Colitis a range of questions about their experience of care and the answers have highlighted what local hospitals are doing well, and what they could do better.

It is also the first time that IBD teams have been able to complete a service self-assessment against the IBD Standards, using the IBD Benchmarking Tool. Teams that have completed this assessment have been provided with detailed information on how their assessment compares with their patient survey results. An overview of this comprehensive report is also published on the IBD UK website.

This is only the beginning. Now it’s time to take these results and make improvements to care. IBD UK will support hospitals with good practice in quality improvement to ensure that the patient voice is heard throughout. We’ll be running a structured programme of workshops and producing a quality improvement toolkit, with templates, case studies and podcasts to help with this process.

The IBD Patient Survey will open again in 2021 and run every two years thereafter, so join us on the journey - together, we can make a real difference.

Rukshana Kapasi
Chair, IBD UK
About this report

This report follows the IBD Standards sections and the patient journey from first symptoms to diagnosis, treatment and ongoing care, as well as how the IBD service should be organised. Each section includes a link to further information, including details on the relevant IBD Standards.

Bar charts in this report show the responses from 22 adult patients with Crohn’s or Colitis using Harrogate District Hospital and how this compares with adult responses from patients across England, as well as the UK. Numbers of respondents are shown for each chart. The numbers of respondents will vary from question to question as not all questions were relevant for all respondents - for example, only those who have been diagnosed within the last two years were asked questions about their diagnosis. Additionally, it was possible to select multiple answers for some questions, so the number of responses may be greater than the number of unique patients. Please note that where there are less than five patients responding, no result will be shown.

The IBD Patient Survey was mostly completed online, between 8th July and 22nd November 2019, with hard copies and translations available, and was promoted through patient organisations and by hospital IBD teams. The total number of respondents across the UK was 10,224, of which 9,786 were adults. Of these adults, 8,125 were from England.

If your hospital completed a self-assessment, a Results Overview report containing selected data from this self-assessment and the IBD Patient Survey will be available from the IBD UK website. Feedback on the reports is welcomed and can be sent to info@ibduk.org
1. Pre-diagnosis

Everyone with IBD should receive an early and accurate diagnosis of their condition. This will mean they get the treatment and support they need sooner and be better able to manage their condition.

More information can be found on this web page [www.ibduk.org/ibd-standards/pre-diagnosis](http://www.ibduk.org/ibd-standards/pre-diagnosis)

Responses included in this section are from 7 patients who have been diagnosed with IBD within the last 2 years.

1.1 How long did it take from the time you first spoke to a healthcare professional about your symptoms to the time your diagnosis was confirmed?

![Bar chart showing time taken to diagnosis]

Your Service | England | UK Average

Patients = 7

1.2 If a GP referred you to a hospital specialist, how long did you wait for your first appointment?

![Bar chart showing wait times for first appointment]

Your Service | England | UK Average

Patients = 7
1.3 Before your diagnosis, did your GP offer you a faecal calprotectin or faecal immunochemical test (FIT) before you were referred to hospital for further investigations?

A faecal calprotectin is a stool test that measures the level of active inflammation in the intestine. A FIT test determines the presence of human haemoglobin in the stool. Both are useful indicators of the likelihood of a diagnosis of Crohn’s or Colitis.

1.4 While waiting for my diagnosis to be confirmed, I was given clear information about what was going to happen next and who to contact if I had any questions.
2. Newly diagnosed

It's essential to get the right treatment and support in place for newly diagnosed patients with IBD. This will give them the best outcomes and help them adjust to living with the condition.

More information can be found on this web page [www.ibduk.org/ibd-standards/newly-diagnosed](http://www.ibduk.org/ibd-standards/newly-diagnosed)

Responses included in this section are from 7 patients who have been diagnosed with IBD within the last 2 years.

### 2.1 Following your assessment, were you assessed for any of the following?

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Your Service</th>
<th>England</th>
<th>UK Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>How severe your Crohn’s or Colitis was, e.g., through tests and asking about symptoms</td>
<td>67% (6)</td>
<td>46%</td>
<td>46%</td>
</tr>
<tr>
<td>Signs of malnutrition and/or nutritional deficiencies, e.g., iron, B12</td>
<td>46% (1,364)</td>
<td>33%</td>
<td>(3)</td>
</tr>
<tr>
<td>How well you were coping emotionally</td>
<td>27% (654)</td>
<td>28%</td>
<td>(832)</td>
</tr>
<tr>
<td>How healthy your bones were, e.g., given a DEXA scan</td>
<td>9% (212)</td>
<td>9%</td>
<td>(269)</td>
</tr>
</tbody>
</table>

### 2.2 Following your assessment, were you offered the opportunity to be referred to any of the following?

<table>
<thead>
<tr>
<th>Referral</th>
<th>Your Service</th>
<th>England</th>
<th>UK Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBD Nurse Specialist</td>
<td>33% (3)</td>
<td>46%</td>
<td>(352)</td>
</tr>
<tr>
<td>Dietitian</td>
<td>47% (1,666)</td>
<td>33%</td>
<td>(3)</td>
</tr>
<tr>
<td>Colorectal Surgeon</td>
<td>21% (516)</td>
<td>21%</td>
<td>(516)</td>
</tr>
<tr>
<td>Mental Health Professional</td>
<td>6% (165)</td>
<td>0%</td>
<td>(0)</td>
</tr>
<tr>
<td>None of the above</td>
<td>0% (0)</td>
<td>0%</td>
<td>(0)</td>
</tr>
</tbody>
</table>
2.3 When you were told you had Crohn’s or Colitis, were you offered any written information about your condition?

![Chart showing information about Crohn's or Colitis]

2.4 I was given enough information about potential treatments and care, including benefits and possible side-effects, to understand the options available to me and make an informed choice.
2.5 Were you involved as much as you wanted to be in decisions about your care and treatment?

![Graph showing involvement in decisions]

2.6 Did you have a written first treatment plan?

![Graph showing written treatment plans]
2. NEWLY DIAGNOSED

2.7 How long after your diagnosis were you able to start treatment?

![Bar chart showing the percentage of patients who started treatment within different time frames:]
- Within 48 hours: 86% (6 patients)
- 2 - 7 days: 46% (670 patients)
- 1 - 2 weeks: 48% (846 patients)
- 3 - 4 weeks: 16% (212 patients)
- More than 4 weeks: 16% (267 patients)

Patients = 7

2.8 When you were told you had Crohn's or Colitis, did a healthcare professional give you any information about relevant patient organisations or charities?

![Bar chart showing the percentage of responses:]
- Crohn's & Colitis UK adult or family information pack: 29% (2 patients)
- Crohn's & Colitis UK parent pack: 33% (33 patients)
- Written information: 9% (979 patients)
- I was given specific contact details and/or a web address: 9% (271 patients)
- Information was mentioned in a conversation: 11% (17% of 326 patients, 45 patients)
- Other: 0% (0 patients)
- None: 43% (3 patients)

Answers = 7 Patients = 7
3. Flare management

When people with IBD experience a flare, they must be able recognise it – and access the right specialist advice and treatment to manage it as quickly as possible.

More information can be found on this web page [www.ibduk.org/ibd-standards/flare-management](http://www.ibduk.org/ibd-standards/flare-management)

Responses included in this section are from 15 patients who had one or more flares in the last 12 months.

3.1 Thinking about your most recent flare, who did you contact in the first instance?

![Graph showing responses](image)

Patients = 15

3.2 How long was it before you received a response?

![Graph showing responses](image)

Patients = 7
3. FLARE MANAGEMENT

3.3 How long after were you able to start treatment?

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Your Service</th>
<th>England</th>
<th>UK Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within 48 hours</td>
<td>86 % (6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 - 7 days</td>
<td>48 % (1,436)</td>
<td>49 % (1,049)</td>
<td></td>
</tr>
<tr>
<td>8 - 14 days</td>
<td>25 % (780)</td>
<td>24 % (915)</td>
<td></td>
</tr>
<tr>
<td>More than 2 weeks</td>
<td>14 % (1)</td>
<td>15 % (410)</td>
<td></td>
</tr>
<tr>
<td>No one came back</td>
<td>0 % (0)</td>
<td>4 % (427)</td>
<td></td>
</tr>
</tbody>
</table>

Patients = 7

3.4 If you had an investigative test in the last 12 months, on average how long did you wait?

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Your Service</th>
<th>England</th>
<th>UK Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 4 weeks</td>
<td>56 % (5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 - 3 months</td>
<td>43 % (1,515)</td>
<td>41 % (1,767)</td>
<td></td>
</tr>
<tr>
<td>4 - 6 months</td>
<td>44 % (1,574)</td>
<td>44 % (1,893)</td>
<td></td>
</tr>
<tr>
<td>7 - 12 months</td>
<td>9 % (92)</td>
<td>10 % (223)</td>
<td></td>
</tr>
<tr>
<td>Over a year</td>
<td>0 % (0)</td>
<td>2 % (26)</td>
<td></td>
</tr>
</tbody>
</table>

Patients = 9
3.5 Have you taken steroid tablets for your Crohn’s or Colitis at any time in the last 12 months?

3.6 What is the longest continuous stretch of time that you have taken a course of steroid tablets within the last 12 months?
4. Surgery and inpatient care

Patient outcomes are better when IBD surgery is timely, led by surgeons with the right expertise, and with effective multidisciplinary working. It’s important that patients fully understand their options and are offered psychological support.

More information can be found on this web page [www.ibduk.org/ibd-standards/surgery](http://www.ibduk.org/ibd-standards/surgery)

For the best outcomes and experience, inpatients with IBD should be admitted to a specialist ward with appropriate facilities and specialist review. They should receive a holistic assessment and be offered appropriate services and support as a result. On discharge, they should have clear information and coordination of care.

More information can be found on this web page [www.ibduk.org/ibd-standards/inpatient-care](http://www.ibduk.org/ibd-standards/inpatient-care)

Responses included in this section are from 5 patients who have been admitted to hospital because of Crohn’s or Colitis-related symptoms in the last 12 months.

**4.1 Did you stay on a ward that cared mainly for patients with bowel conditions, also known as a ‘gastroenterology’ ward?**

![Bar chart showing responses to the question on ward type.](chart.png)
4. SURGERY AND INPATIENT CARE

4.2 When you needed to use a toilet or bathroom, was a suitable one located close by on your ward?

4.3 When admitted to hospital, were you assessed for any of the following?

Answers = 6  Patients = 5
4.4 If you were referred for an operation, how long did you wait?

4.5 I was given information in a format that helped me understand the benefits and risks of surgery.
4.6 Were you offered the opportunity to speak to an IBD Nurse Specialist while you were an inpatient?

4.7 I was given clear information to help me manage my care after discharge from hospital including medicines, post-operative wound and stoma care.

Unfortunately, no information can be included here for this service due to insufficient numbers of patients (less than 5) responding to the IBD Patient Survey.
5. Ongoing care and monitoring

As IBD is a fluctuating, lifelong condition, people need ongoing care to live well with their condition. A personalised care plan will empower patients, support self-management and help primary and secondary care communicate effectively.

More information can be found on this web page [www.ibduk.org/ibd-standards/ongoing-care-monitoring](http://www.ibduk.org/ibd-standards/ongoing-care-monitoring)

Responses included in this section are from 22 patients.

5.1 Have you been provided with any of the following?

![Bar chart showing percentage of patients provided with information or contact details.](chart1)

5.2 Have you ever contacted your IBD service advice line?

![Bar chart showing percentage of patients who have contacted the IBD service advice line.](chart2)
5.3 When I contact the NHS IBD service advice line, I get a response by the end of the next working day.

5.4 Do you have contact with an IBD nurse specialist?
5.5 Has a healthcare professional provided you with any of the following?

5.6 We discuss my wider life goals and priorities, as part of planning my Crohn's or Colitis care.
5. ONGOING CARE AND MONITORING

5.7 Do you have a personalised written care plan?

![Bar chart showing the percentage of patients who have a personalised written care plan.](image)

Patients = 20

5.8 Do you have a regular review for your Crohn's or Colitis, regardless of whether you are well or not?

![Bar chart showing the percentage of patients who have regular reviews.](image)

Patients = 22
5. ONGOING CARE AND MONITORING

5.9 During appointments, I am asked about fatigue / tiredness and treatment options are discussed to manage this.

![Bar chart showing responses](chart1.png)

- **Strongly agree**: 14% (3)
- **Tend to agree**: 17% (1,276)
- **Neither agree nor disagree**: 18% (4)
- **Tend to disagree**: 20% (1,501)
- **Strongly disagree**: 23% (5)

Patients = 22

5.10 During appointments, I am asked about pain and treatment options are discussed to manage this.

![Bar chart showing responses](chart2.png)

- **Strongly agree**: 20% (4)
- **Tend to agree**: 24% (1,831)
- **Neither agree nor disagree**: 31% (2,348)
- **Tend to disagree**: 31% (2,851)
- **Strongly disagree**: 35% (7)

Patients = 20
5. ONGOING CARE AND MONITORING

5.11 During appointments, I am asked about my mental health or emotional wellbeing and treatment options are discussed.

5.12 During appointments, I am asked about IBD related complications and/or conditions outside of the gut and treatment options are discussed.
5.13 Have you been offered any of the following opportunities by any NHS service to learn more about treating and/or living with Crohn’s or Colitis?

- 11% (833) have been offered the opportunity to attend an IBD open day at my local hospital
- 10% (704) have been offered the opportunity to attend a course on IBD
- 9% (732) have been offered the opportunity to attend an educational talk

5.14 I have the information and skills to confidently manage everyday symptoms and live as well as possible.
6. IBD Service

Everyone living with IBD should have safe, consistent, high quality, personalised care. A well-organised and managed local IBD service is essential to delivering this.

More information can be found on this web page [www.ibduk.org/ibd-standards/the-ibd-service](http://www.ibduk.org/ibd-standards/the-ibd-service)

Responses included in this section are from 21 patients.

6.1 I am supported by a team of IBD specialists who help me manage my condition.

![Bar chart showing responses to the statement about being supported by a team of IBD specialists.](chart1)

6.2 My treatment and care are well-coordinated by my IBD team and any other services I see for other medical services I have.

![Bar chart showing responses to the statement about treatment and care coordination.](chart2)
6.3 I have access to specialist advice or support with nutrition if I should need it.

6.4 Have you been offered any of the following opportunities to participate in a clinical trial(s) and/or IBD research?
Acknowledgements

Thank you to everyone who shared their experiences of care and to those who contributed to the development of the IBD Patient Survey and production of this report through focus groups and feedback.