This report shows results from the IBD Benchmarking Tool 2019/2020, a new way to assess how well services across the UK are providing care against the IBD Standards 2019. It includes information from a self-assessment completed by the IBD Team and from an IBD Patient Survey completed by 22 patients who use this service. This report has been produced by IBD UK, a partnership of patient and professional organisations working together for everyone affected by IBD.

**The Service in Numbers**

Covers a population of **200,000**

Supports **525** adult IBD patients

Of which **186** were diagnosed in the past 12 months

**The IBD Team**

The IBD Standards define the ideal make-up of the IBD team in terms of full-time roles. Shown below are the actual numbers for this IBD team, with ideal numbers based on population size in brackets beneath.

- **1 Consultant Gastroenterologist** ([IBD Standards = 1.6])
- **0 Stoma Nurses** ([IBD Standards = 1.2])
- **0 Radiologists** ([IBD Standards = 0.4])
- **0 Administrators** ([IBD Standards = 0.4])
- **0 Dietitians** ([IBD Standards = 0.8])
- **1.5 IBD Nurse Specialists** ([IBD Standards = 2])
- **0 Consultant Colorectal Surgeons** ([IBD Standards = 16])
- **0 Psychologists** ([IBD Standards = 0.4])
- **0 Histopathologists** ([IBD Standards = 0.8])
- **0 Pharmacists** ([IBD Standards = 0.5])

**Quality of Care**

Overall, how would you rate the quality of your Crohn’s or Colitis care over the last 12 months? [22 responses for this service]

Rated as "Excellent" or "Very good" by **41%** of patients

Rated as "Fair" or "Poor" by **32%** of patients

Rated as "Good" by **27%** of patients

These results have been made publicly available to support clinicians, patients and commissioners to improve quality of care for IBD patients. Thank you to everyone who responded to the IBD Patient Survey 2019. The next IBD Patient Survey will run in 2021.
**Patient Journey Overview**

**Pre-diagnosis**

- All* patients with IBD are seen within 4 weeks from their first referral
  - [Achieved by 38% of services]
  - Not yet achieved

**Newly Diagnosed**

- 43% of newly diagnosed patients are offered written information on their condition
  - [7 responses for this service]
  - [All UK survey responses: 65%]

- 29% of patients were given clear information about next steps and who to contact while waiting for their diagnosis to be confirmed
  - [7 responses for this service]
  - [All UK survey responses: 41%]

- New diagnoses and the care plan that has been agreed are communicated to CPs within 1 week
  - [Achieved by 60% of services]

**Flare Management**

- All* IBD patients contacting the IBD advice line get a response by the end of the next working day
  - [Achieved by 88% of services]
  - Not yet achieved

- All* IBD patients have access to review by the IBD team within a maximum of 5 working days
  - [Achieved by 88% of services]
  - Achieved

- All* IBD patients have access to steroid use recorded
  - Guidance about steroid use is communicated to primary care
  - [Achieved by 45% of services]
  - Not yet achieved

- Data is routinely collected and audited on patients receiving more than 1 course of steroids a year
  - [Achieved by 41% of services]
  - Not yet achieved

- All* inpatients with IBD are seen by a consultant gastroenterologist and/or colorectal surgeon on a specialist ward within 24 hours of admission
  - [Achieved by 73% of services]
  - Achieved

- All* elective IBD surgery takes place within 18 weeks
  - [Achieved by 63% of services]
  - Achieved

*All = More than 90% of patients
**Patient Journey Overview**

**Ongoing Care and Monitoring**

**33%** of patients have contact with an IBD nurse specialist

- [21 responses for this service]
- [All UK survey responses: 84%]

**55%** of patients have regular reviews regardless of their health

- [22 responses for this service]
- [All UK survey responses: 64%]

**All IBD patients have a personalised care plan based on a holistic needs assessment**

- [Achieved by 58% of services]

**48%** of patients believe their care is well-coordinated between their GP and gastroenterologist

- [21 responses for this service]
- [All UK survey responses: 42%]

**9%** of patients discuss wider life and priorities, as part of planning their care

- [22 responses for this service]
- [All UK survey responses: 30%]

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**The IBD Service**

**All patients have access to non-acute endoscopy and imaging within 4 weeks, and within 24 hours for patients who are acutely unwell or require admission to hospital**

- [Achieved by 76% of services]

**IBD patients are directly involved in service development**

- [Achieved by 71% of services]

**18%** of patients have been given the opportunity to feedback on their care in the past 12 months

- [22 responses for this service]
- [All UK survey responses: 21%]

**Protocols are in place to support transition to adult services for young people with IBD**

- [Achieved by 37% of services]

**All patients with confirmed IBD are recorded in an electronic clinical management system**

- [Achieved by 26% of services]

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*All = More than 90% of patients*