



# IBD BENCHMARKING TOOL 2019/2020 RESULTS OVERVIEW

ALDER HEY CHILDREN'S HOSPITAL

[www.ibduk.org](http://www.ibduk.org)

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 26 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.

Key



IBD Patient Survey 2019



IBD Service Self-Assessment 2019/2020

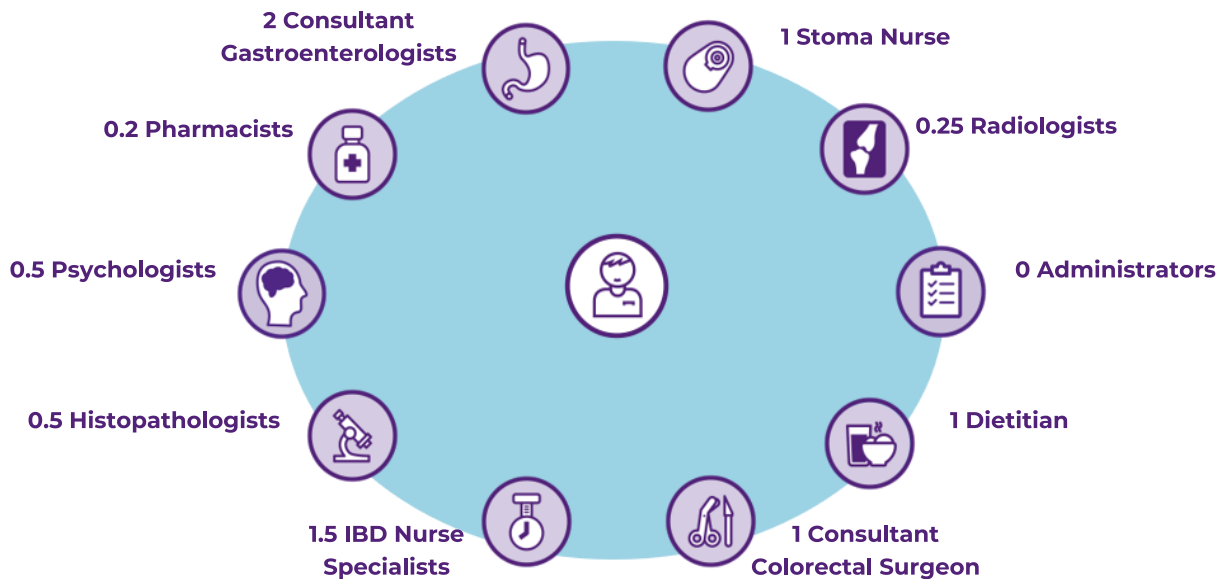
## The Service in Numbers

Covers a population of  
**3,000,000**

Supports  
**360**  
paediatric IBD  
patients

Of which  
**75**  
were diagnosed in the  
past 12 months

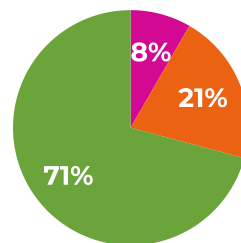
## The IBD Team



## Quality of Care

Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months? [24 responses for this service]

Rated as "Excellent" or "Very good" by 71% of patients



Rated as "Fair" or "Poor" by 8% of patients

Rated as "Good" by 21% of patients

We will partner with our patients and guardians to improve experience, education and empowerment to make informed decisions in their care to optimise outcomes. We will host a study day, invite engagement for formation of patient-parents' panels and further explore opportunities to invite patient feedback to incorporate best practice.



## Patient Journey Overview

Key



IBD Patient Survey 2019



IBD Service Self-Assessment 2019/2020



### Pre-diagnosis

All\* patients with IBD are seen within 4 weeks from their first referral



[Achieved by 75% of services]

Not yet achieved

### Newly Diagnosed



**100%** of newly diagnosed patients are offered written information on their condition  
[14 responses for this service]  
[All UK survey responses: 96%]



**77%** of patients were given clear information about next steps and who to contact while waiting for their diagnosis to be confirmed

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

New diagnoses and the care plan that has been agreed are communicated to GPs within 1 week



[Achieved by 59% of services]

Not yet achieved



## Flare Management

All\* IBD patients contacting the IBD advice line get a response by the end of the next working day



[Achieved by 86% of services]

Achieved



Guidance about steroid use is communicated to primary care and steroid use recorded

Achieved

[Achieved by 59% of services]



All\* IBD patients have access to review by the IBD team within a maximum of 5 working days

Achieved

[Achieved by 94% of services]

Data is routinely collected and audited on patients receiving more than 1 course of steroids a year



[Achieved by 12% 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 86% of services]

Achieved



All\* elective IBD surgery takes place within 18 weeks

Achieved

[Achieved by 91% of services]

## Surgery and Inpatient Care





### Patient Journey Overview

Key



IBD Patient Survey 2019



IBD Service Self-Assessment 2019/2020



### Ongoing Care and Monitoring



**96%** of patients have contact with an IBD nurse specialist

[26 responses for this service]  
[All UK survey responses: 97%]

**68%** of patients have regular reviews regardless of their health

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



All\* IBD patients have a personalised care plan based on a holistic needs assessment  
[Achieved by 60% of services]



Not yet achieved



**32%** of patients believe their care is well-coordinated between their GP and gastroenterologist

[25 responses for this service]  
[All UK survey responses: 47%]

**33%** of patients discuss wider life and priorities, as part of planning their care

[24 responses for this service]  
[All UK survey responses: 47%]



### 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



Not yet achieved

[Achieved by 63% of services]

IBD patients are directly involved in service development



[Achieved by 20% of services]

Not yet achieved



**21%** of patients have been given the opportunity to feedback on their care in the past 12 months

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



Achieved

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

[Achieved by 78% of services]

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



[Achieved by 74% of services]

Achieved