IBD BENCHMARKING TOOL 2019/2020 RESULTS OVERVIEW

EDINBURGH ROYAL HOSPITAL FOR SICK CHILDREN 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 34 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

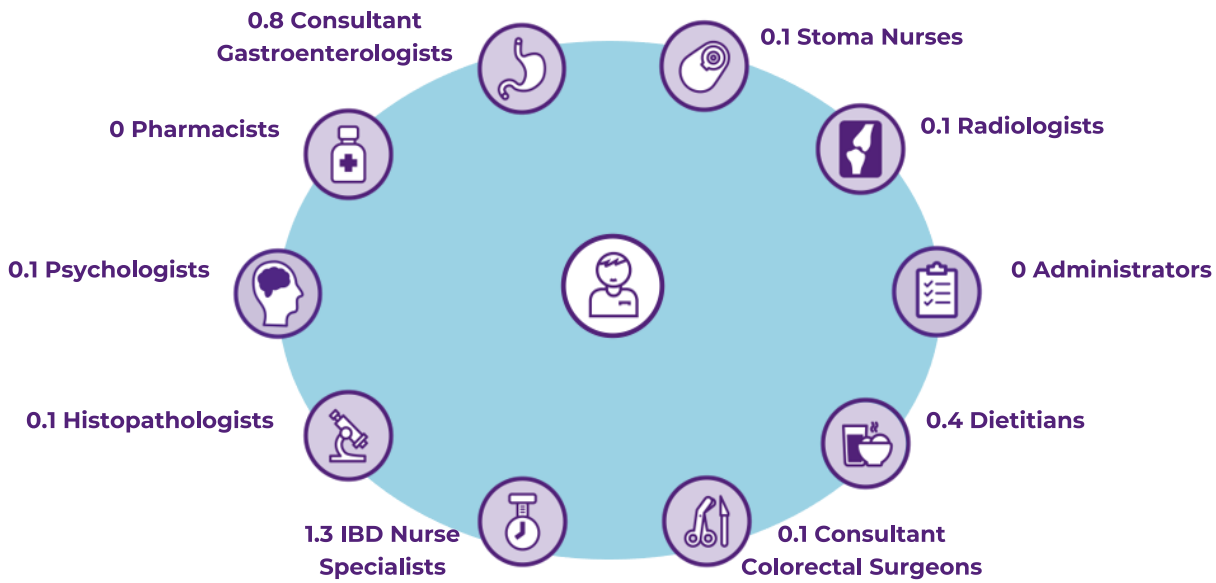
The Service in Numbers

Covers a population of
1,400,000

Supports
160
paediatric IBD patients

Of which
32
were diagnosed in the past 12 months

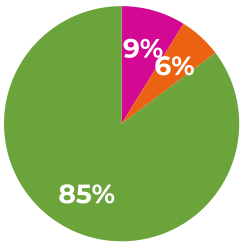
The IBD Team



Quality of Care

Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months? [34 responses for this service]

Rated as "Excellent" or "Very good" by 85% of patients



Rated as "Fair" or "Poor" by 9% of patients

Rated as "Good" by 6% 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.

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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]
Achieved

78% of patients were given clear information about next steps and who to contact while waiting for their diagnosis to be confirmed
[18 responses for this service]
[All UK survey responses: 64%]

Newly Diagnosed

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

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
Not yet achieved
[Achieved by 59% of services]

Achieved
All* IBD patients have access to review by the IBD team within a maximum of 5 working days
[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]
Not yet achieved

Achieved
All* elective IBD surgery takes place within 18 weeks
[Achieved by 91% of services]

Surgery and Inpatient Care

*All = More than 90% of patients

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Ongoing Care and Monitoring

97% of patients have contact with an IBD nurse specialist
[34 responses for this service]
[All UK survey responses: 97%]

97% of patients have regular reviews regardless of their health
[34 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

46% of patients believe their care is well-coordinated between their GP and gastroenterologist
[26 responses for this service]
[All UK survey responses: 47%]

61% of patients discuss wider life and priorities, as part of planning their care
[33 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
[Achieved by 63% of services]
Achieved

IBD patients are directly involved in service development
[Achieved by 20% of services]
Not yet achieved

22% of patients have been given the opportunity to feedback on their care in the past 12 months
[32 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

*All = More than 90% of patients