IBD UK
Strategy
Partnership
Quality Improvement

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# Section 1: The IBD Service

### Statement 1.1

Patients should be cared for by a defined IBD multidisciplinary team led by a named consultant adult or paediatric gastroenterologist.

#### Statement 1.2

Multidisciplinary team meetings should take place regularly to discuss appropriate patients.

### Statement 1.3

Protocols should be in place which clearly define the local transition service and the personnel responsible.

### Statement 1.4

The IBD service should have a leadership team which includes a senior clinician, IBD nurse specialist and manager, who have responsibility for managing, monitoring and developing the service.

### Statement 1.5

The IBD leadership team should work with an expert pharmacist in IBD to ensure good medicines governance, including medicines optimisation and cost-effectiveness.

### Statement 1.6

IBD teams should promote continuous quality improvement and participate in local and national audit.

#### Statement 1.7

Patients and parents/carers should have a voice and direct involvement in the development of the service.

#### Statement 1.8

All patients with confirmed IBD should be recorded in an electronic clinical management system and data provided to the national IBD Registry.

### Statement 1.9

Clear information about IBD, the local IBD service and patient organisations should be accessible in outpatient clinics, wards, endoscopy and day care areas.



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# Statement 1.10

Endoscopic assessment and ultrasound/MRI/CT/ contrast studies should be accessible within four weeks, and within 24 hours where patients are acutely unwell or require admission to hospital.

## Statement 1.11

Histological processing and reporting should take place routinely within five working days or within two working days for reporting of urgent biopsy samples.

### Statement 1.12

Agreed protocols should be in place for pre-treatment tests, vaccinations, prescribing, administration and monitoring of immunomodulator and biological therapies.

### Statement 1.13

Patients should be fully informed about the benefits and risks of, and the alternatives to, immunomodulator and biological therapies, including surgery.

### Statement 1.14

Patients receiving immunomodulator and biological therapies should be offered vaccinations in accordance with clinical guidelines.

# Statement 1.15

All forms of nutritional therapy should be available to IBD patients, where appropriate, including exclusive enteral therapy for Crohn's Disease and referral to services specialising in parenteral nutrition.

### Statement 1.16

All members of the IBD team should develop competencies and be educated to a level appropriate for their role, with access to professional support and supervision.

### Statement 1.17

IBD services should encourage and facilitate involvement in multidisciplinary research through national or international IBD research projects and registries.



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# Section 2: Pre-Diagnosis

### Statement 2.1

Clear pathways and protocols for investigating children and adults with persistent lower gastrointestinal symptoms should be agreed between primary and secondary care and should include guidance on the use of faecal biomarker tests in primary care to aid rapid diagnosis.

# Statement 2.2

Patients who are referred with suspected IBD should be seen within four weeks, or more rapidly if clinically necessary.

### Statement 2.3

Patients presenting with acute severe colitis should be admitted to a centre with medical and surgical expertise in managing IBD that is available at all times.

### Statement 2.4

All patients should be provided with a point of contact and clear information about pathways and timescales while awaiting the outcome of tests and investigations.



# Section 3: Newly Diagnosed

### Statement 3.1

All newly diagnosed IBD patients should be seen by an IBD specialist and enabled to see an adult or paediatric gastroenterologist, IBD nurse specialist, specialist gastroenterology dietitian, surgeon, psychologist and expert pharmacist in IBD as necessary.

### Statement 3.2

After diagnosis, all patients should have full assessment of their disease, nutritional status, bone health and mental health, with baseline infection screen, in order to develop a personalised care plan.

# Statement 3.3

Patients should be supported to make informed, shared decisions about their treatment and care to ensure these take their preferences and goals fully into account.



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#### Statement 3.4

After diagnosis, all outpatients with IBD should be able to start a treatment plan within 48 hours for moderate to severe symptoms and within two weeks for mild symptoms.

#### Statement 3.5

Patients should be signposted to information and support from patient organisations

# Statement 3.6

GPs should be informed of new diagnoses and the care plan that has been agreed within 48 hours.



# Section 4: Flare Management

### Statement 4.1

Local treatment protocols and clear pathways should be in place for the management of IBD patients experiencing flares and include advice for primary care.

### Statement 4.2

All patients with IBD should be provided with clear information to support self-management and early intervention in the case of a flare.

### Statement 4.3

Rapid access to specialist advice should be available to patients to guide early flare intervention, including access to a telephone/email advice line with response by the end of the next working day.

### Statement 4.4

Patients with IBD should have access to review by the IBD team within a maximum of five working days and be able to escalate/start a treatment plan within 48 hours of review.

### Statement 4.5

Steroid treatment should be managed in accordance with guidelines and audited on an ongoing basis, with clear guidance to primary care.



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# Section 5: Surgery

### Statement 5.1

Patients should have access to coordinated surgical and medical clinical expertise, including regular combined or parallel clinics with a specialist colorectal surgeon (paediatric colorectal surgeon where appropriate) and IBD gastroenterologist.

# Statement 5.2

Elective IBD surgery should be performed by a recognised colorectal surgeon who is a core member of the IBD team in a unit where such operations are undertaken regularly.

### Statement 5.3

In the absence of relevant local expertise, paediatric patients or adult patients requiring complex surgery should be referred to a specialist unit.

### Statement 5.4

Patients with IBD being considered for surgery should be provided with information in a format and language they can easily understand to support shared decision making and informed consent and offered psychological support.

#### Statement 5.5

Prior to elective surgery, a full assessment and optimisation of medical treatment and physical condition should be undertaken to minimise risk of complications and aid post-operative recovery.

### Statement 5.6

Patients should be counselled about laparoscopic resection as an option, when appropriate, in accordance with clinical guidelines.

# Statement 5.7

Patients and parents/carers should be provided with information about post-operative care before discharge, including wound and stoma care, and offered psychological support.

### Statement 5.8

Elective surgery for IBD should be performed as soon as the patient's clinical status has been optimised and within 18 weeks of referral for surgery.



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# Section 6: Inpatient Care

### Statement 6.1

Patients requiring inpatient care relating to their IBD should be admitted directly, or transferred within 24-48 hours, to a designated specialist ward area under the care of a consultant gastroenterologist and/or colorectal surgeon.

### Statement 6.2

Where ensuite rooms are not available, inpatients with IBD should have a minimum of one easily-accessible toilet per three beds on a ward.

### Statement 6.3

Inpatients with IBD must have 24-hour rapid access to critical care services if needed.

#### Statement 6.4

Children and adults admitted as inpatients with acute severe colitis should have daily review by appropriate specialists.

### Statement 6.5

For patients with acute severe colitis, stool culture and Clostridium difficile assay should be performed upon admission to exclude infectious causes of colitis.

### Statement 6.6

For patients admitted with acute severe colitis, limited flexible sigmoidoscopy, when indicated, should be performed without bowel preparation by an experienced endoscopist.

### Statement 6.7

All patients with acute severe colitis not settling on intravenous steroids should be assessed regularly by a consultant adult/paediatric colorectal surgeon and a decision made with the patient and adult/paediatric gastroenterologist on day three to escalate to rescue therapy or undertake a colectomy.

### Statement 6.8

On admission, patients with IBD should have an assessment of nutritional status, mental health and pain management using validated tools and be referred to services and support as appropriate.



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#### Statement 6.9

All IBD inpatients should have access to an IBD nurse specialist.

### Statement 6.10

All IBD inpatients should have their prescribed and over the counter medications reviewed on admission by a pharmacist who has access to a expert pharmacist in IBD for advice, with regular review of medications during their inpatient stay and at discharge.

### Statement 6.11

Clear written information about follow up care and prescribed medications should be provided before discharge from the ward and communicated to the patient's IBD clinical team and GP within 48 hours of discharge.



# Section 7: Ongoing Care

#### Statement 7.1

A personalised care plan should be in place for every IBD patient, with access to an IBD nurse specialist and telephone/email advice line

### Statement 7.2

Patients should be supported in self-management, as appropriate, through referral or signposting to education, groups and support.

### Statement 7.3

Clear protocols should be in place for the supply, monitoring and review of medication across primary and secondary care settings.

### Statement 7.4

Pain and fatigue are common symptoms for IBD patients and should be investigated and managed using a multidisciplinary approach including pharmacological, non-pharmacological and psychological interventions where appropriate.

# Statement 7.5

Any reviews and changes of treatment in primary or secondary care should be clearly recorded and communicated to all relevant parties within 48 hours.



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# Statement 7.6

Patients or parents/carers should be offered copies of clinical correspondence relating to their/their child's treatment and care.

### Statement 7.7

All IBD patients should be reviewed at agreed intervals by an appropriate healthcare professional and relevant disease information recorded.

# Statement 7.8

A mechanism should be in place to ensure that colorectal cancer surveillance is carried out in line with national guidance and that patients and parents/carers are aware of the process.