

IBD Benchmarking Tool Guidance for Service Self-Assessment

(See www.ibduk.org for more on the IBD Standards, guidelines and benchmarking FAQs)

IBD Benchmarking Tool Questions and Guidance

This guidance document has been put together to help teams to prepare for the IBD Benchmarking service self-assessment. It should help identify what information is needed for this and therefore who needs to be involved, whether in the self-assessment meeting or by providing specific information. Apart from the first section, most questions only require 'Yes' or 'No' answers. You can complete the self-assessment in any order, return to it as many times as you like and add comments in the "Anything else" spaces at the end of each section at any point.

ABOUT YOU

What role does the person who has registered for this benchmarking have in the IBD service?

Who is involved in the benchmarking process?

A checklist of potential participants is provided. Ideally, at least a gastroenterologist, nurse, manager and patient/carer would be involved in the self-assessment meeting.

ABOUT YOUR IBD SERVICE

What size population does your IBD service cover?

If your service operates across more than one hospital, please give the total population covered by the service. Note: this refers to all patients, not just those with IBD. You can get these numbers from your hospital's JAG/GRS submission.

Who is the Clinical Lead for the IBD service?

Name and contact details are requested for our records.

What age groups does your IBD service cover?

Adults

Paediatrics (defined as up to the age of 16 and those who are in the process of transition to adult services)

How many adult/paediatric patients does your IBD service manage?

This is the total number of patients your IBD service is responsible for – the figure can be an estimate or from a database/registry

Do you have any patients under 16 managed in your service? [for adult services only]

If so, how many over the past 12 months?

How many IBD inpatients has your service managed over the past 12 months?

This question relates to the number of IBD-related hospital admissions (either for planned or emergency procedures, requiring at least one overnight stay) over the past year. The figure can be an estimate or from a database/registry

How many newly diagnosed IBD patients has your service seen in the past 12 months?

Are these figures estimates or from a database/register?

The numbers above may be estimated or drawn from a local database or from the IBD Registry – you are asked to indicate which.

Is your service a tertiary referral centre?

Are you providing services across hospital sites?

Does your IBD service involve team members, e.g. Clinical Lead, IBD nurse specialists, working across more than one hospital to deliver a combined IBD service?

Please list each hospital your IBD service includes?

If more than one hospital is involved in providing a combined IBD service, you are asked to list each of these.

THE IBD SERVICE

MULTIDISCIPLINARY TEAM AND COORDINATED CARE

Statement 1.1

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

Is there a defined IBD multidisciplinary team in your service, led by a named adult or paediatric gastroenterologist?

This would include core members who all have a special interest in IBD or gastroenterology and work together, for example, attending MDTs.

Which specialists are members of your team and how much time do they allocate to IBD work including attending the MDT?

You are asked to indicate numbers for each specialism in whole time equivalent terms. Adult services are asked if their team meets the full requirements of the IBD Standards: <https://ibduk.org/ibd-standards/the-ibd-service/the-ibd-multidisciplinary-team>

Can direct referral to support services take place or can this only occur through primary care? Are agreed and clearly defined clinical criteria in place to support this and, if so, are these reviewed regularly with feedback/audit?

Pathways are 'clearly defined' if they are documented, agreed between the relevant services, and enable efficient referral and coordination between the services for IBD patients.

Statement 1.2

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

Do IBD multidisciplinary meetings take place?

These can be part of an established meeting such as a gastrointestinal/surgical meeting, but would involve members of the IBD team discussing IBD patients with specific needs?

How frequently do these take place? (Weekly/fortnightly/less often?) Do they have clearly defined criteria in terms of who attends the meetings and which patients are discussed? Is there administrative support for coordination and recording? Are meetings attended by medical, radiological, surgical and nursing representatives for at least 80% of meetings? Are decisions recorded?

Do all core members of the IBD team attend IBD multidisciplinary team meetings? Is there clear feedback to all patients discussed, with written outcomes reported in the patient's records?

Statement 1.3

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

Are protocols in place for transition?

Transition protocols are documents which outline the approach to transition taken by the service, its aims and what processes are in place to support transition for young people with IBD.

Do transition protocols clearly define the local transition service and include a clinical transition lead and named transition coordinator for all patients undergoing transition?

Do all patients have an individual transition plan and the opportunity to attend joint transition clinics and is audit undertaken?

All elements should be included.

THE LEADERSHIP TEAM AND QUALITY IMPROVEMENT

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.

Does the IBD service have a leadership team? A leadership team will comprise of individuals who work together with defined responsibility for managing, monitoring and developing the service.

Does the leadership team include a senior clinician, IBD nurse specialist and manager?

A senior clinician could include a consultant gastroenterologist or consultant colorectal surgeon. The leadership team should include both clinical and managerial input for this question to receive a “Yes” answer.

Do the leadership team have clearly identified roles and actions? This would include the development of a documented annual plan for the service, with named leads for all key activities and clear timescales for completion? Is there an identified structure for regular documented meetings? This might include a business meeting every 8 weeks, an annual governance meeting and an annual review and strategy meeting, for example.

Statement 1.5

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

Do the IBD leadership teamwork with a pharmacist?

Through their management and monitoring of the service, does the IBD leadership teamwork with a pharmacist specifically in relation to medicines management and optimisation?

Do they work with an expert or consultant pharmacist in IBD (or equivalent), with annual formulary review?

An expert pharmacist in IBD will have achieved or be working towards Royal Pharmaceutical Society faculty advanced level 2 with a specialism in IBD. A consultant pharmacist or equivalent in IBD will have achieved or be working towards fellowship of the Royal Pharmaceutical Society.

Annual review of the formulary would cover the drugs agreed to be routinely initiated by clinicians in the service and stocked by the Pharmacy department or prescribed through FP10 prescription forms.

Does the IBD leadership teamwork with a consultant pharmacist or equivalent in IBD on annual protocol/policy review with actions and outcomes, to actively develop pharmacy services within IBD?

Annual protocol/policy review would include the overall approach of the service to ensuring that drug treatments are being prescribed, administered and monitored appropriately and advising on the use of high cost biologics.

Statement 1.6

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

Does auditing take place within the IBD service?

Does audit and reporting take place in a planned way?

Is there a defined schedule of audits that are undertaken and a process of reporting on these that is followed within the service? This should be produced with engagement from the whole team, have senior leadership support, be regularly reviewed and updated and be published on the trust/health board website. Auditing can include local audit of specific aspects and outcomes of the service and/or participation in national audit activities (for example, the IBD Biologics Audit).

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.

Is there electronic recording of any IBD patients and/or any data provided to the IBD Registry? This could be in the form of a local database and/or submission of data to the UK IBD Registry. Does this cover at least 90% of all IBD patients managed by the service, with data added on a regular and ongoing basis? Is data provided regularly to the UK IBD Registry through quarterly uploads?

PATIENT ENGAGEMENT AND INFORMATION PROVISION

Statement 1.7

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

Is patient feedback gathered in addition to comments cards/feedback forms and the friends & family test?

This could be through local surveys, focus groups, patient engagement events or discussion/open forum sessions at open days, for example.

Are IBD patients involved in service development, e.g. through an IBD Patient Panel or specific project groups?

Are IBD patients directly involved in co-producing service development initiatives? Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.

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.

Is information available about the local IBD service and ways that patients can be involved?

Is information provided in a range of formats, including face-to-face, written, visual, online and audio/video.

Is accessibility of information audited, involving a specific review of the range of information produced against set standards of accessibility, including patient feedback.

INVESTIGATIONS AND TREATMENT

Statement 1.10

Endoscopic assessment and ultrasound/MRI/CT/contrast studies should be accessible within 4 weeks, and within 24 hours where patients are acutely unwell or require admission to hospital.

How accessible are endoscopy and imaging in both non-acute and acute situations? Questions ask about timeframes for >90% of patients. The IBD Registry is a data source for this.

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.

How accessible is histological processing and reporting in both routine and urgent situations? Questions ask about timeframes for >90% of patients.

Statement 1.12

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

Is there written departmental guidance on immunomodulatory and biological therapy management, e.g. treatment pathways?

Does this include pre-treatment tests, vaccinations, prescribing, administration and monitoring?

Is there locally published audit of outcomes from immunomodulatory 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.

Do patients receive written information on all potential options?

Do 90% of patients being considered for immunomodulators and biological therapies have the opportunity to discuss benefits, risks and alternatives with both medical and surgical specialists?

Is patient feedback gathered and reviewed?

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.

Is there provision for access to a dietitian for advice and nutritional support? Are exclusive enteral nutrition for Crohn's Disease and referral to services specialising in parenteral nutrition part of any relevant agreed treatment pathways.

Are outcomes of nutritional therapy for IBD patients audited?

**PROFESSIONAL
EDUCATION,
TRAINING,
SUPERVISION AND
RESEARCH**

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.

Are professional development opportunities encouraged for all members of the IBD team? These might include study days to upskill or keep up to date with changing practice and technology and/or opportunities to develop advanced practice skills.

Does each member of the IBD team have a development plan and access to support and supervision?

Is specific resource allocated to support development and a clear assessment process is in place to evaluate each member of the team, including patient feedback.

Statement 1.17

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

Are patients recruited to observational or Registry studies and/or UK Clinical Research Network clinical trials at this site?

Is there at least one principal investigator?

Are patients recruited into commercial and non-commercial UK Clinical Research Network clinical trials, with at least one chief investigator at the site?

PRE-DIAGNOSIS

PATHWAYS AND INFORMATION

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.

Is there an agreed referral pathway for suspected IBD between primary and secondary care? What is the timeframe for referral to specialist assessment for >90% of patients? Does this take place within 8 weeks? Does it take place within 4 weeks? Is there access to faecal calprotectin in primary care for adults?

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.

Does the service have medical and surgical expertise in managing IBD that is available at all times? If not, are patients with acute severe colitis routinely admitted to a centre with medical and surgical expertise in managing IBD? Are outcomes audited?

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.

Is there a clear process for ensuring that all patients are provided with information about likely timescales and details of who to contact with any queries or concerns while awaiting the outcome of tests and investigations? Do >90% of patients receive this information? Is patient feedback of the process reviewed?

NEWLY DIAGNOSED

ACCESS TO IBD SPECIALISTS AND HOLISTIC ASSESSMENT

Statement 3.1

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

Are >90% of newly diagnosed IBD patients seen by a member of the IBD team in a specialist clinic?

Are newly diagnosed IBD patients seen in a dedicated IBD clinic with access to adult/paediatric gastroenterologist, IBD nurse specialist, surgeon, dietitian, psychologist and expert pharmacist in IBD as necessary?

Access may be as part of a joint clinic or through a defined assessment/referral process.

Does annual audit include patient reported outcomes following new diagnosis and access to the specialist team?

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.

Is there an agreed departmental process for disease/needs assessment for IBD patients after diagnosis?

Does the process include nutritional status and bone health, with baseline infection screen?

Does this include mental health assessment?

SHARED DECISION-MAKING AND TREATMENT INITIATION

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.

Is written information about IBD and a range of treatments, including booklets from patient organisations, made available to patients?

This could be in clinics, at open days and patient education sessions and/or as part of consultations.

Is this provided routinely to 90% of patients as part of consultations to support shared decision-making?

Are patients supported to be actively involved in management decisions about their care, with a clear, structured process for patients to discuss their treatment with the multidisciplinary team?

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.

Are clear processes in place for treatment initiation for newly diagnosed outpatients with IBD?

Are these documented, shared and understood by all relevant staff, including endoscopists and all members of the IBD team?

Are >90% of newly diagnosed outpatients with IBD able to start a treatment plan within 48 hours for severe symptoms and within two weeks for mild symptoms?

Is patient feedback reviewed and processes audited in relation to treatment initiation for outpatients with IBD?

SUPPORT AND INFORMATION TO PATIENTS AND GPs

Statement 3.5

Patients should be signposted to information and support from patient organisations.

Is information about patient organisations available in all settings?

This would include leaflets and/or information sheets and/or booklets, as well as signposting online/via email, through clinics, endoscopy and infusion areas.

Is this available in a variety of formats and proactively offered to >90% of all patients?

Is patient feedback reviewed about information provided on patient organisations and an action plan put in place to address any gaps?

Statement 3.6

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

**For >90% of all newly diagnosed patients, how quickly are GPs informed – within one week? Within 48 hours?
Is the process evaluated and feedback sought from GPs?**

FLARE MANAGEMENT

FLARE PATHWAYS AND PROTOCOLS

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.

These questions are for adult services only.

Are locally agreed pathways in place for flare management which provide clear guidance to GPs on flare management and when and how they should contact the IBD team?

Have local pathways for flare management been agreed between primary and secondary care for local use?

These may be based on nationally-agreed templates such as those on the IBD UK website and at rcgp.org.uk/ibd.

Are outcomes of flare management pathways audited, with feedback gathered from patients, GPs and members of the IBD team to assess their effectiveness?

INFORMATION TO SUPPORT SELF- MANAGEMENT AND EARLY INTERVENTION

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.

Is information provided to >90% of patients on flare management (e.g. flare card)?

Is information on flare management individualised? This could form part of a care plan.

Is patient feedback on flare management information collected and reviewed? This may, for example, be in the form of an online survey accessed through a link printed on the flare information provided and/or through a specific review by a group of patients.

**RAPID ACCESS TO
SPECIALIST ADVICE
AND TREATMENT
PLAN**

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.

Is there an agreed process for patients to contact the team using telephone and/or email during a flare?

This should be a clearly identifiable number and/or email address which is included in information about the IBD service and provided to patients, available on the hospital website and included in the Crohn's & Colitis UK ['Find an IBD nurse specialist' map](#).

Is the advice line open 5 days a week?

Are details clearly communicated to all patients? What arrangements are in place to cover the advice line during staff absence/leave? Are >90% of patients able to receive a response by the end of the next working day?

Is this audited and patient feedback reviewed?

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.

Is there an agreed process for access to specialist review within 5 working days?

This can be over the telephone or face-to-face as appropriate. The treatment plan should start within 48 hours of the specialist review. Review could include different members of IBD team as appropriate.

Are >90% of patients able to access specialist review within five working days and able to escalate/start a treatment plan within 48 hours of review?

Are outcomes audited and patient feedback recorded?

STEROID MANAGEMENT

Statement 4.5

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

Is agreed guidance about steroid use for IBD patients available to all staff involved in diagnosing and treating IBD patients?

This should be based on clinical guidelines and be available to all members of the IBD team and other health care professionals involved in the care of IBD patients including endoscopists and GPs.

Is data routinely collected and audited on patients receiving excess steroids?

This is defined in accordance with ECCO and UK guidelines as the presence during the 12 month period preceding the clinic visit of 1 or more of: (1) the prescription of >1 steroid course or (2) inability to wean steroids below 10 mg/day prednisolone or 3 mg/day budesonide within 3 months of starting steroids or (3) disease flare within 3 months of stopping steroids.

SURGERY

SURGICAL/MEDICAL JOINT WORKING

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.

Can parallel consultant clinic appointments be arranged for individual patients with medical and surgical team members so that they can see a physician in an IBD clinic and a colorectal surgeon in a clinic on the same morning or afternoon?

Do joint consultant surgical/medical combined clinic consultations occur?

Are there established, regular, joint consultant surgical/medical combined clinics?

These will be easily accessible for appropriate patients and take place frequently, e.g. every 2 months.

**SURGERY BY
APPROPRIATE
SPECIALISTS**

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.

Is elective IBD surgery for >90% of patients undertaken by a recognised colorectal surgeon?

Is it undertaken by a recognised colorectal surgeon who is a core member of the IBD team?

They should have a substantial amount of their working time devoted to IBD.

Are surgical outcomes audited for elective IBD surgery?

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.

Are patients requiring complex surgery referred to a specialist surgeon and/or unit (if appropriate)?

This would be likely to include revision and excision pouch surgery, rectovaginal fistula and Kock pouch.

Are pathways in place to routinely refer patients requiring complex surgery to an appropriate specialist unit?

Is audit of process and outcomes undertaken, including patient feedback?

Statement 5.4

**INFORMATION AND
SUPPORT**

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.

Are patients with IBD who are considering surgery directed to patient information leaflets, decision aids or other media to support decision making and informed consent?

Are these offered routinely to >90% of patients with IBD who are considering surgery and are patients enabled to discuss the options fully as part of shared decision-making?

Are the information materials available in a range of formats and language to suit individual needs and preferences, with patient feedback audited to identify and address any gaps in provision?

Statement 5.6

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

Is the option of laparoscopic surgery discussed with patients undergoing surgery where a laparoscopic procedure is appropriate?

This may require referral to another unit.

Is laparoscopic surgery offered by one surgical member of the IBD team for patients undergoing surgery where a laparoscopic procedure is appropriate?

Is it offered by all surgical members of the IBD team?

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.

Is information available about post-operative care before discharge?

Are >90% of patients and parents/carers routinely provided with information about post-operative care before discharge, including wound and stoma care?

This should be in a format that is easily understood by the patient and supported by discussion - including with other patients and appropriate specialists, such as a stoma nurse.

Are patients offered psychological support?

**ASSESSMENT,
OPTIMISATION AND
WAITING TIMES**

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.

Are pathways in place with supporting services and medical/surgical coordination to enable full assessment and optimisation of patients prior to surgery?

Is there access to radiological facilities for abscess drainage, a full nutrition team and joint surgical/medical input to optimise medical therapy?

This should include access to other specialists, e.g. obstetrics, cardiology, as required.

Is a clear, documented optimisation plan followed for >90% of patients who have correctable risk factors?

Full assessment should include:

- A nutritional risk assessment – with referral to a dietitian or nutrition support team for appropriate nutritional support and/or supplementation
- Reduction or stopping of medications including steroids and biological therapy where feasible
- Resolution of sepsis following radiological intervention and antibiotic therapy
- Drainage of any abscesses and associated treatment for people with fistulising Crohn's
- Expert pathological assessment
- Risk of venous thromboembolism (VTE)

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.

Does elective surgery take place <18 weeks following referral?

How soon after a patient's clinical status has been optimised is elective surgery for IBD performed?

Optimisation involves assessment for, and correction of, risk factors as identified above and ensuring that health status is as good as it can be prior to surgery to aid rehabilitation and improve outcomes.

INPATIENT CARE

SPECIALIST WARD AND 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.

Is a process in place to ensure that patients requiring inpatient care relating to their IBD are seen by an IBD specialist on a gastroenterology ward?

An IBD specialist may be a consultant gastroenterologist and/or a colorectal surgeon.

How soon after admission are patients requiring inpatient care relating to their IBD seen by an IBD specialist on a gastroenterology ward?

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.

What access do inpatients with IBD have to appropriate and easily accessible toilets?

Questions are asked in terms of numbers per bed.

Toilets should be within easy reach of the ward beds, be clean, have full-length doors, be well-ventilated and have separate facilities for men and women to minimise embarrassment and anxiety. There should also be enough space for people to change and dispose of stoma equipment comfortably.

MANAGEMENT OF ACUTE SEVERE COLITIS

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.

Do patients with acute severe colitis have daily review by appropriate specialists?

Appropriate specialists would include consultant adult or paediatric gastroenterologist and consultant adult or paediatric colorectal surgeon.

Do >90% of patients with acute severe colitis have stool culture and Clostridium difficile assay performed on admission?

Is audit undertaken?

Statement 6.7

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

Are patients with acute severe colitis not settling on intravenous steroids assessed by a consultant colorectal surgeon and a decision made on day 3 to escalate to rescue therapy or undertake a colectomy?

Does assessment take place regularly (not just on day three) for >90% of relevant patients and is a joint decision made between patient, gastroenterologist and colorectal surgeon about next steps in accordance with protocols set out in clinical guidelines (e.g. BSG, ECCO)?

Is audit undertaken?

ASSESSMENT, MEDICATION REVIEW AND FOLLOW UP

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.

Are nutritional status, mental health and pain management assessed for patients with IBD on admission, with pathways in place for onward referral as appropriate? Are validated tools used?

Statement 6.9

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

Are clear mechanisms in place for identification to the IBD team/nurse specialist when a patient with IBD is admitted?

Is the IBD team/nurse specialist advised when a patient with IBD is admitted?

Are outcomes of inpatient support/advice given recorded inpatient records?

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 specialist pharmacist for advice, with regular review of medications during their inpatient stay and at discharge.

What level of access to support does the ward pharmacist have access to?

1). Advanced generalist pharmacist - to seek advice for medication review and optimisation? An advanced generalist pharmacist is highly experienced but is not a specialist.

2). Expert pharmacist in IBD, or equivalent - to seek advice for medication review and optimisation and personalised consultation. An expert pharmacist in IBD or equivalent has achieved, or is working towards, the Royal Pharmaceutical Society advanced level 2.

3). Consultant pharmacist in IBD, or equivalent - on admission and during their stay for medication review, optimisation and personalised consultation? A consultant pharmacist in IBD or equivalent, has achieved, or is working towards fellowship of the Royal Pharmaceutical Society faculty. They may work across more than one hospital unit.

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.

Is written information provided about follow up care before discharge from the ward?
Is this provided to >90% of patients, including a number/person to contact?
Does this information include details of all prescribed medications and a date for clinical review?
Is this emailed to the GP on discharge/within 48 hours?

ONGOING CARE

ADVICE, SUPPORT AND CARE PLANNING

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

Do consultations allow for discussion with patient about wider life goals and aims from treatment?

Is a defined care planning process in place for all patients?

Personalised care and support planning is a systematic process based around 'better conversations' between the person/patient and health care professionals and a focus on 'what matters' to them and their individual strengths and needs. It is a continuous process not a one-off event.

Do all patients have a personalised care plan?

Statement 7.2

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

Do educational and networking opportunities exist to support self-management, with signposting to externally run educational opportunities?

These may, for example, be through direction to local patient organisation activities and/or hospital-run events.

Are a wide range of educational and networking opportunities available to support self-management including an annual service open day?

These might include both external and hospital-organised events and activities.

Are educational and networking opportunities available in ways that suit individual needs and preferences (e.g. one-to-one, group-based, open days, web-based)?

These would be discussed as part of consultations/care planning to support the individual to access opportunities that best meet their own needs and preferences.

SHARED CARE

Statement 7.3

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

Are shared care protocols in place for the review and monitoring of all relevant IBD medications across primary and secondary care?

These should clearly define requirements for prescribing and monitoring of medications and who will carry this out, including frequency of monitoring and what action should be taken in the event of abnormal results.

Are these agreed by primary and secondary care and in use, with all relevant information recorded? They should be understood and agreed by - as well as easily accessible to - all parties, including patients.

This may be through publication on the hospital website, for example.

Are arrangements for shared care discussed and agreed with patients, with written information provided?

This should include clear explanation of the roles and responsibilities of everyone involved, and when patients should be referred to hospital care with contact details for the IBD team, so that they know how to get in touch if needed.

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.

How long does it take to communicate any reviews and changes of treatment in primary or secondary care?

Correspondence from secondary to primary care should include:

- Main diagnosis/diagnoses, specifying type and location of IBD and date of diagnosis
- Date(s) of surgery
- Secondary diagnosis/diagnoses e.g. anaemia/vitamin D deficiency/osteoporosis/ extraintestinal manifestations
- Date of last endoscopy with findings and date of next planned/routine endoscopy
- Date of next planned contact with secondary care
- Current medical therapy including any previous treatments with thiopurines, methotrexate or biologics and reasons for discontinuation
- Recommended length of current medical therapy
- Treatment recommendations in case of a flare – mesalazine/prednisolone/budesonide/calcium and vitamin D and who to contact if treatment is initiated in primary care
- Contact details for the IBD team/service
- [RCGP IBD Toolkit](#) for further advice and guidance for primary care.

All correspondence should be copied to patients, and/or parents/carers, and recorded in the patient's care plan.

HOLISTIC MONITORING AND REVIEW

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.

Are protocols in place for the investigation of patients with pain and fatigue?

Are IBD patients regularly asked about pain and fatigue at outpatient appointments and reviews?

This may be through relevant symptom questionnaires and PROMs, for example (e.g. [the fatigue checklist](#)).

Statement 7.7

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

Is a protocol in place for determining the frequency of review and monitoring of IBD patients?

This should include how often review should take place in different circumstances - for example, for those with mild proctitis on no medication to those with severe disease on biologics - and by whom (GP, consultant gastroenterologist, IBD nurse), ensuring that patients are not lost to follow-up.

Is a process in place to ensure that all relevant information is discussed and recorded at each review?

This would include:

- Symptom assessment and disease control
- Medication review, including effectiveness, patient experience and adherence and therapeutic monitoring using agreed protocols
- Review of long-term complication risk factors, such as colorectal cancer surveillance, smoking and osteoporosis
- Wellbeing and emotional support needs
- Identification and discussion of commonly identified ongoing issues for patients, even when in remission, such as diet, fertility and pregnancy, travelling with IBD, frailty and concurrent medications, continence concerns, fatigue and ongoing pain
- Discussion about relapse prevention and what to do in a flare
- Clear, documented agreements about when the next investigation, blood test or review is planned

Is this made available to patients?

For example, this could be provided in writing as part of a care plan and/or given to patients before a clinic visit.

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.

These questions are for adult services only

Is a clear, documented process in place for colorectal cancer surveillance?

Is this process and timescales communicated to patients, with reminders as appropriate?

Is this audited?

If you have any queries or difficulties at any point, please don't hesitate to get in touch with us at info@ibduk.org.

IBD UK Benchmarking Team