IBD Benchmarking Tool Service Self-Assessment Questions

About your service / demographics

What size population does your IBD service cover?

Who is the Clinical Lead for the IBD service?

What age groups does your IBD service cover?

How many adult IBD patients does your service manage?

How many paediatric IBD patients does your service manage?

Do you have any patients under 16 managed in your service?

How many patients under the age of 16 have been managed by your service over the past 12 months?

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

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

Are these figures estimates, or from a database/register?

Is your service a tertiary referral centre?

Are you providing services across hospital sites?

Please list each hospital your IBD service includes

The IBD service

The multidisciplinary team and coordinated care

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

Does your IBD team meet the full requirements according to the IBD Standards?

Which of the following are included within your IBD team?

How many whole time equivalent (WTE) consultant gastroenterologists are in your team?

How many whole time equivalent (WTE) consultant colorectal surgeons are in your team?

How many whole time equivalent (WTE) IBD nurse specialists are in your IBD team?

How many whole time equivalent (WTE) clinical nurse specialists with special interest and competency in stoma therapy and ileoanal pouch management are in your team?

How many whole time equivalent (WTE) expert pharmacists in IBD are in your team?

How many whole time equivalent (WTE) dietitians are in your team?

How many whole time equivalent (WTE) psychologists / psychiatrists with a special interest in gastroenterology are in your team?

How many whole time equivalent (WTE) radiologists with a special interest in gastroenterology are in your team?

How many whole time equivalent (WTE) histopathologists with a special interest in gastroenterology are in your team?

How many whole time equivalent (WTE) administrators are in your team?

Can the service refer directly to essential supporting services (e.g. rheumatologist, dermatologist, ophthalmologist) for patients with IBD?

Are agreed and clearly defined clinical criteria in place for referral to essential supporting services (e.g. rheumatologist, dermatologist, ophthalmologist) for patients with IBD?

Are referral criteria reviewed regularly with feedback/audit?

Do IBD multidisciplinary team meetings take place?

Do IBD multidisciplinary team meetings take place frequently (weekly or fortnightly) with clearly defined criteria and administrative support, attended by medical, radiological, surgical and nursing representatives, with decisions recorded?

Do all core members of the IBD team attend IBD multidisciplinary team meetings, with clear feedback to patients discussed?

Are protocols in place for transition?

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?

The IBD service

Leadership team and quality improvement

Does the IBD service have a leadership team?

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

Do the leadership team have clearly identified roles and actions?

Does the IBD leadership team work with a pharmacist?

Does the IBD leadership team work with an expert or consultant pharmacist in IBD (or equivalent) with annual formulary review?

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

Does auditing take place within the IBD service?

Does audit and reporting take place in a planned way?

Is there an annual audit plan and cycle, with formally reported outcomes and actions?

Is there electronic recording of any IBD patients and/or any data provided to the IBD Registry?

Is there complete and regular electronic recording of all IBD patients?

Is data provided regularly to the UK IBD Registry?

The IBD service

Patient Engagement and Information Provision

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

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?

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

Is this available in a variety of media with audit of accessibility?

Is it co-produced with patients?

The IBD service

Investigations and treatment

Are endoscopy and imaging accessible within 6 weeks, and within 48 hours where patients are acutely unwell or require admission to hospital?

Is non-acute endoscopy and imaging accessible within 5 weeks, with endoscopy accessible within 48 hours and imaging within 24 hours where patients are acutely unwell or require admission to hospital?

Is non-acute endoscopy and imaging accessible within 4 weeks, with access to both endoscopy and imaging within 24 hours for patients who are acutely unwell or require admission to hospital?

Does histological reporting and processing take place routinely within 10 working days, with urgent histopathology reports within 6 working days?

Does histological reporting and processing take place routinely within 8 working days, with urgent histopathology reports within 4 working days?

Does histological reporting and processing take place routinely within 6 working days, with urgent histopathology reports within 2 working days?

Is there some written departmental guidance on immunomodulatory and biological therapy management?

Is there complete written departmental guidance on immunomodulatory and biological therapy management?

Is there locally published audit of outcomes from immunomodulatory and biological therapies?

Do patients receive written information on immunomodulatory and biologic therapies and commonly undertaken surgical procedures?

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

Is patient feedback gathered and reviewed?

Is nutritional therapy available to IBD patients?

Are all forms of nutritional therapy available to IBD patients as part of agreed treatment pathways?

Are outcomes of nutritional therapy for IBD patients audited?

The IBD service

Professional education, training, supervision and research

Are professional development opportunities encouraged for all members of the IBD team?

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

Is there protected time and funding to support development and access to clearly identified supervision with reported review of practice and clinical outcomes for each member of the IBD team?

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 at this site?

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

Pre-diagnosis

Is there an agreed referral pathway for suspected IBD between primary and secondary care?

Is there access to faecal calprotectin in primary care, with referral to specialist assessment within 8 weeks? [adult]

Does referral to specialist assessment take place within 8 weeks? [paediatric]

Are >90% of patients with suspected IBD seen within 4 weeks of referral?

Does the service have medical and surgical expertise in managing IBD that is available at all times?

Are patients with acute severe colitis routinely admitted to a centre with medical and surgical expertise in managing IBD?

Is this medical and surgical expertise in managing IBD available at all times?

Are outcomes audited in relation to management and appropriate onward referral of patients with acute severe colitis?

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?

Is information provided to patients about likely timescales and details of who to contact with any queries or concerns while awaiting the outcome of tests and investigations?

Is patient feedback of this process reviewed?

Newly diagnosed

Access to IBD specialists & holistic assessment

Are all newly diagnosed IBD patients seen by a member of the IBD team?

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

Are patient reported outcomes recorded following new diagnosis and access to the specialist team?

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?

Newly diagnosed

Shared decision making and treatment initiation

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

Is this provided routinely to >90% of patients as part of the consultation 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?

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

Do these processes ensure that newly diagnosed outpatients with IBD are able to start a treatment plan within 48 hours for moderate to severe symptoms and within two weeks for mild symptoms?

Are these processes audited, including patient feedback?

Newly diagnosed

Support and information to patients and GPs

Is information about patient organisations available in all settings?

Is this routinely offered to all patients?

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

Are new diagnoses and the care plan that has been agreed communicated to GPs within one week?

Are new diagnoses and the care plan that has been agreed communicated electronically to GPs within 48 hours?

Is this process evaluated and feedback sought from GPs?

Flare management

Flare pathways and protocols

Are locally agreed pathways in place for flare management?

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

Are the outcomes of flare management pathways audited?

Flare management

Information to support self-management and early intervention

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

Is individualised information on flare management provided?

Is patient feedback collected and reviewed on flare management information?

Flare management

Rapid access to specialist advice and treatment plan

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

Is the advice line open 5 days a week and are details clearly communicated to all patients?

Do >90% of patients receive a response by the end of the next working day?

Is there an agreed process for access to specialist review within 5 working days and escalation/initiation of a treatment plan within 48 hours?

Are >90% of patients able to access specialist review within 5 working days?

Are outcomes audited and patient feedback recorded?

Flare management

Steroid management

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

Is this guidance communicated to primary care and steroid use recorded?

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

Surgery

Surgical / medical joint working

Can parallel consultant clinic appointments be arranged for individual patients with medical and surgical team members?

Do joint consultant surgical/medical combined clinic consultations occur?

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

Surgery

Surgery by appropriate specialists

Is elective IBD surgery undertaken by a recognised colorectal surgeon?

Is the colorectal surgeon who undertakes elective IBD surgery a core member of the IBD team?

Are surgical outcomes audited for elective IBD surgery?

Does the service offer complex surgery?

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

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

Is audit of process and outcomes undertaken?

Surgery

Information and 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 given routinely to all patients with IBD who are considering surgery?

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

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

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

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

Is information available for patients/carers about post-operative care before discharge?

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

Are patients offered psychological support?

Surgery

Assessment, optimisation and waiting times

Are pathways in place 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?

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

Does elective IBD surgery take place <18 weeks following referral?

Is elective surgery for IBD performed within eight weeks of the patient's clinical status having been optimised?

Is elective surgery performed within four weeks of the patient's clinical status having been optimised?

Inpatient care

Admission to specialist ward / care and toilets

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

Are >90% of patients seen within 48 hours of admission by an IBD specialist on a gastroenterology ward?

Are >90% of patients seen within 24 hours of admission by an IBD specialist on a gastroenterology ward?

Do inpatients with IBD have access to at least one clean, appropriate and easily accessible toilet per six beds?

Do inpatients with IBD have access to at least one clean, appropriate and easily accessible toilet per four beds?

Do inpatients with IBD have access to at least one clean, appropriate and easily accessible toilet per three beds?

Inpatient care

Management of acute severe colitis and access to critical care

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

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

Is audit undertaken?

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

Are >90% of these patients assessed regularly by a consultant colorectal surgeon in accordance with established protocols, and the decision made jointly between the surgeon, gastroenterologist and patient on day three to escalate to rescue therapy or undertake a colectomy?

Is audit undertaken?

Inpatient care

Assessment, medication review and follow up

Is nutritional status assessed for patients with IBD on admission, with pathways in place for onward referral as appropriate?

Is pain management assessed for IBD patients on admission, with pathways in place to ensure appropriate onward referral?

Is mental health assessed for all IBD patients on admission, with pathways in place for onward referral as appropriate?

Are there 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 in patient records?

Does the ward pharmacist have access to an advanced generalist pharmacist to seek advice for medication review and optimisation?

Does the ward pharmacist have access to an expert pharmacist in IBD, or equivalent, to seek advice for medication review and optimisation and personalised consultation?

Do the patient and ward pharmacist have access to a consultant pharmacist in IBD, or equivalent, on admission and during their stay for medication review, optimisation and personalised consultation?

Are patients provided with clear, written information about follow up care, including a number / person to contact in the event of clinical urgency before discharge from the ward?

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 and monitoring

Advice, support and care planning

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

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

Do all patients have a personalised care plan?

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

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

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?

Ongoing care and monitoring

Shared care

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

Are these agreed between primary and secondary care, with all relevant information recorded?

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

Are relevant changes of treatment in primary or secondary care recorded and communicated within two weeks?

Are relevant changes of treatment in primary or secondary care recorded and communicated within one week?

Are relevant changes of treatment in primary or secondary care recorded and communicated within 48 hours?

Ongoing care and monitoring

Holistic monitoring and review

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

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

Are non-pharmacological treatment options available for pain and fatigue?

Is a clear protocol in place for determining how frequently review and monitoring of IBD patients should take place?

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

Is this information made available to patients?

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

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

Is this audited?