

A08/S/c

**2013/14 NHS STANDARD CONTRACT
FOR COLORECTAL: COMPLEX INFLAMMATORY BOWEL DISEASE
(ADULT)**

PARTICULARS, SCHEDULE 2- THE SERVICES, A- SERVICE SPECIFICATIONS

Service Specification No.	A08/S/c
Service	Colorectal: Complex Inflammatory Bowel Disease (Adult)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Inflammatory Bowel Disease (IBD) is the umbrella term for a group of inflammatory conditions of the colon and the small intestine. The two major forms of IBD are Crohn's Disease and Ulcerative Colitis. Other forms of IBD include Collagenous Colitis; Lymphocytic Colitis; Ischaemic Colitis; Diversion Colitis; Behçet's disease; and indeterminate Colitis.

The prevalence of IBD is estimated to be 400 cases per 100,000 head of population. IBDs are common causes of gastrointestinal morbidity. The total cost of IBD to the NHS has been estimated at £720 million, based on an average cost of £3,000 per patient per year with up to half of total costs for relapsing patients.

Typically, first line treatment for IBD is medical management in a secondary care setting where anti-inflammatory drugs and monoclonal antibodies are used to control the disease. Common surgical approaches include removal of the colon and formation of a stoma, or the creation of a replacement colon (an ileo-anal pouch) by reshaping the end of the small intestine.

A small proportion of patients require complex surgery either because of their previous surgical history or because of the nature of their disease. These patients should receive surgery in an expert tertiary centre that undertakes sufficient volumes of specialised activity to achieve the best outcomes for the patient. The aim of

this specification is to address this need to ensure patients with complex IBD surgical problems are dealt with by units that are adequately resourced and skilled and who manage sufficient cases to maintain expertise. The key principles of surgery are to preserve the length of the small intestine and to avoid permanent stoma formation.

There is clear guidance concerning the principles of management of these often complex clinical problems. There is increasing evidence of difference in surgical outcomes between centres.

Inflammatory Bowel Disease Audit: Round 2

http://www.rcplondon.ac.uk/sites/default/files/uk_ibd_audit_2nd_round_2008_report_national_results_for_the_organisation_process_of_adult_ibd_care_in_the_uk.pdf

European Crohn's and Colitis Organisation Guidelines

British Society of Gastroenterology Guidelines

http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/ibd/ibd_2011.pdf

Volume analysis of outcome following restorative proctocolectomy

<http://www.ncbi.nlm.nih.gov/pubmed/21072850>

2. Scope

2.1 Aims and objectives of service

The aim of this surgical service is to restore health and quality of life in patients with complex IBD with disease patterns unsuitable for or resistant to medical therapies.

Specifically this will include:

- bowel surgery for patients at risk of short bowel syndrome that would require long term parenteral feeding (greater than 28 day duration)
- surgical management of multi-focal small bowel disease which may result in short bowel syndrome
- revisional surgery on ileo-anal pouches
- excision of ileo-anal pouch surgery
- surgical management of Neoplasia arising in a Perianal Fistulae in a patient with Crohn's Disease
- surgical reconstruction of an unhealed perineum requiring plastic surgical expertise.

2.2 Service description/care pathway

The specialised surgical service for IBD comprises the following elements:

- Referral of patients with IBD requiring a surgical procedure as outlined above.
- Review by a colorectal surgeon with a special interest in IBD and discussion in a multi-disciplinary meeting.
- Identification of the most appropriate treatment option, taking into account the individual needs of the patient
- Provision of the identified intervention
- Follow-up
- Discharge

Multi-disciplinary Team (MDT) Review

Prior to MDT discussion, the patient will be reviewed in an out-patient clinic by a member of the specialist MDT who will undertake a detailed history and examination, and initiate appropriate investigations. Patients will then be discussed at the MDT and a treatment plan identified.

Patients will then be reviewed in clinic and a treatment plan finalised. At this outpatient appointment the patient has an opportunity to discuss the pros and cons of interventions. The patient will be given written information regarding the planned procedure, the hospital stay and immediate post-operative information regarding recovery. They will be introduced to the principle surgeon and nurse specialist, as the link worker, with a telephone contact for the team. A summary of the discussions and management plan will be provided to the GP and be offered to the patient if they wish to have a copy.

Surgery

Specialised procedures for IBD will largely be delivered as inpatient procedures. Patients will be accommodated on appropriate surgical/gastro-intestinal mixed medical/surgical wards where nurses have the appropriate competencies to ensure excellent wound care/stoma care and to look after patients requiring parenteral nutrition.

Follow-up Review

Patients will be followed up by the specialist unit post-operatively. This will ordinarily involve one follow-up attendance. In some cases, 'tidy-up' surgery or closure of a stoma may be necessary. This will be performed by the specialised service if clinically indicated, otherwise the patient will be discharged back to their referring centre at which point they will exit the specialist service.

The specialised service will ensure a developed network approach to allow the smooth transfer of patients. This is crucial as patients will have built up trust and dependence on personnel within the local (referring) unit – who will also continue to

look after the patient following the specialised surgical spell. The specialist nurses in both units need to ensure continuity of care and support for the patient and carer.

The MDT will consist of a minimum of :

- 2 colorectal surgeons with a sub-specialist interest in IBD
- 2 gastroenterology physicians
- a member of a nutrition team (eg dietician/ pharmacist/specialist nurse)
- histopathologist with a special interest in IBD
- radiologist with a special interest in IBD
- specialist inflammatory bowel disease nurse
- specialist stoma nurse
- access to psychiatric / psychological support
- management support for coordinating MDT and data collection.

The MDT will meet no less frequently than once per month to ensure patients are discussed in a timely manner.

Access and exit to service

Referral by a colorectal surgeon or gastroenterologist with an interest in IBD to the specialist service and not to a named consultant.

Patients will remain under the care of the specialised service:

- until the specialist unit deems no surgical intervention is appropriate and it is safe to refer the patient back to the local service or on to another service.
- until, following surgery, patients are discharged back to local services, usually at the first outpatient attendance following discharge from the inpatient surgical spell. Occasionally “tidy up” surgery or closure of a stoma may be necessary. This will be performed by the specialised unit if clinically indicated. If not the patient will be returned to the referring unit.
- unless they become ineligible for NHS funded care or they die whilst undergoing treatment.
- unless they elect to discontinue receiving care provided by this service.

2.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in *Who Pays?: Establishing the responsible commissioner* and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges):

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/ :.DH_127393

(*Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England)

Specifically, this service is for adults with complex inflammatory bowel disease that requires surgical intervention.

2.4 Any acceptance and exclusion criteria

This service will accept referrals from colorectal surgeons/gastroenterologists who look after patients with IBD. Referrals will be made to the specialised service as a whole and not to individual named consultant surgeons.

Referral criteria (at least one of the following must apply):

- Patients requiring bowel surgery who are at risk of short bowel syndrome requiring long term (greater than 28 day) parenteral nutrition.
- Patients requiring surgical management of multifocal small bowel disease which might result in short bowel syndrome.
- Patients requiring revisional surgery to an existing ileo-anal pouch
- Patients requiring excision of an ileo-anal pouch
- Patients with Crohn's disease who develop a neoplasia in a perianal fistulae
- Patients requiring surgical reconstruction of an unhealed perineum requiring plastic surgical expertise.

Exclusion criteria:

- Patients under the age of 18.
- Patients with established Type II or III Intestinal Failure – who should be referred to the Specialised Intestinal Failure service.

2.5 Interdependencies with other services

Co-located services

Services which must be provided from the same healthcare setting (i.e. the same hospital site) as the specified service are as follows:

- Services
- Full general medical services
- Gastroenterology services
- Stoma therapy services
- Specialist and interventional radiology

Interdependent services

Services which the specified service will require access to routinely, for care provided during the period of the pathway described in this specification, but for which there is no absolute requirement for these services to be physically co-

located on the same healthcare delivery site are:

- Plastic surgery

Related services

The service forms part of a pathway of care provided in a number of settings by different providers. The service will need to maintain excellent communication with other agencies and services providing care to the patient including their General Practitioner and secondary care Cancer Centre who will be responsible for the longer-term follow-up of patients treated by this service.

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

National Institute for Health and Clinical Excellence (NICE) clinical guideline (CG)152 Crohn's Disease: Management in adults, children and young people.

British Society of Gastroenterology (BSG) guidelines / audit define standards

Specific standards set out in detail in Inflammatory Bowel Disease Audit: Round 2

http://www.rcplondon.ac.uk/sites/default/files/uk_ibd_audit_2nd_round_2008_report_-_national_results_for_the_organisation_process_of_adult_ibd_care_in_the_uk.pdf

All surgical treatment should be recorded on a local database

Units will be required to take part in the British Society of Gastroenterology IBD audit

Patients who undergo ileo-anal pouch formation/revision/excision will have their data entered in the Association of Coloproctology of Great Britain and Ireland (ACPGBI) database.

4. Key Service Outcomes

TBC