

Organisational audit – Round 4

Paediatric IBD service help notes

Useful information

More information that can be found via the 'Supporting documents' section of the web tool include:

- [Quick start guide](#)
- [How to log in](#)
- [Frequently asked questions](#)
- [Hard copy of the audit tool \(Paediatric\)](#)
- [How to access resources in the shared document store](#)

Further supporting information that you may find helpful is available via the 'Resources' section on the website. Here you can access reports, guidelines and much more.

Section 1. Demographics		
Question number	Data item	Help notes
DEM 1.1	How many IBD patients does your service manage?	Include <u>all</u> patients (inpatients and outpatients of any age) managed by your service
DEM 1.6	How many new IBD patients have you seen in the last 12 months?	Of those patients in DEM1.1, how many were completely new to your service (not necessarily newly-diagnosed)?
DEM 1.8	How many patients aged 16 and under at the date of admission, were discharged from the care of paediatric services between 1 January and 31 December 2013 with a primary diagnosis of ulcerative colitis? (with LOS >24hrs)	<ul style="list-style-type: none"> - Include only patients with a primary admission of ulcerative colitis that were discharged from hospital during the period specified - LOS >24hrs = a length of stay of greater than 24 hours - Refer to the supporting guidance on the web tool for the ICD10 and OPCS codes related to the admission and surgical questions
DEM 1.9	How many of these patients were readmitted within 30 days of discharge? (with LOS >24hrs)	- Refer to the supporting guidance on the web tool for the ICD10 and OPCS codes related to the admission and surgical questions
DEM 1.10	How many patients aged 16 and under at the date of admission, were discharged from the care of paediatric services between 1 January and 31 December 2013 with a primary diagnosis of Crohn's disease? (with LOS >24hrs)	<ul style="list-style-type: none"> - Include only patients with a primary admission of Crohn's disease that were discharged from hospital during the period specified - LOS >24hrs = a length of stay of greater than 24 hours - Refer to the supporting guidance on the web tool for the ICD10 and OPCS codes related to the admission and surgical questions
DEM 1.11	How many of these patients were readmitted within 30 days of discharge? (with LOS >24hrs)	- Refer to the supporting guidance on the web tool for the ICD10 and OPCS codes related to the admission and surgical questions
DEM 1.12	How many patients aged 16 and under at the date of admission, were discharged from the care of paediatric services between 1 January and 31 December 2013 had an operation where the primary indication was ulcerative colitis?	<ul style="list-style-type: none"> For questions DEM 1.12 and DEM 1.13, we have included a list of OPCS-4 codes relating to IBD surgery that you can use to help answer these questions (refer to supporting documentation on the web tool). - LOS >24hrs = a length of stay of greater than 24 hours
DEM 1.13	How many patients aged 16 and under (at the date of admission) discharged from the care of paediatric services between 1 January and 31 December 2013 had an operation where the primary indication was Crohn's disease?	<ul style="list-style-type: none"> For questions DEM 1.12 and DEM 1.13, we have included a list of OPCS-4 codes relating to IBD surgery that you can use to help answer these questions (refer to supporting documentation on the web tool). - LOS >24hrs = a length of stay of greater than 24 hours
DEM 1.14	Do surgeons perform ileo-anal pouch surgery on site?	Answer 'Yes' if this surgery is carried out at your site, even though you may not have carried one out in the last year
DEM 1.15	How many ileo-anal pouch operations were performed between 1 January and 31 December 2013?	Answer '0' if you do not perform ileo-anal operations or have not performed one in the last one year

DEM 1.16	Were the majority of these ileo-anal pouch surgeries carried out by a paediatric surgeon in conjunction with an adult colorectal surgeon?	If you answered 'no' to DEM1.14, answer 'no' here
DEM 1.17	How many WTE paediatric gastroenterologists are there on site?	All staffing levels should be based on those in post at 31st Dec 2013 (DEM 1.17 to DEM1.25)
DEM 1.21	How many WTE stoma nurses are there on site?	The number of WTE stoma nurses is the only information required here, irrespective of time spent with IBD patients. Stoma nurse will also include nurses who are predominantly involved in the continuity of care of patients with ileo-anal pouches.
DEM 1.23	How many WTE administrators are attached to the IBD team?	Administrative support for the IBD team eg MDT meetings, data entry and audit. Do not include routine secretarial support provided for consultants or IBD nurses
DEM 1.29	How many patients with Crohn's disease were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Infliximab primarily for the treatment of Crohn's disease. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if kept up to date
DEM 1.30	How many patients with ulcerative colitis were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Infliximab primarily for the treatment of ulcerative colitis. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if it has been kept up to date
DEM 1.31	How many patients with IBD-unspecified were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Infliximab primarily for the treatment of IBD-unspecified. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if it has been kept up to date
DEM 1.32	How many patients with Crohn's disease were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Adalimumab primarily for the treatment of Crohn's disease. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if it has been kept up to date
DEM 1.33	How many patients with ulcerative colitis were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Adalimumab primarily for the treatment of ulcerative colitis. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if it has been kept up to date

DEM 1.34	How many patients with IBD-unspecified were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	Only include patients that were newly-started on Adalimumab primarily for the treatment of IBD-unspecified. The treatment can have been started as an outpatient or an inpatient. You can obtain this number from the biological therapies audit data you have entered if it has been kept up to date
DEM 1.35	Are the figures in DEM 29 and DEM 34 an estimate (enter 'e') or from a database/register (enter 'd')?	You can obtain these numbers from the biological therapies audit data you have entered if it has been kept up to date

Section 2. Patient experience		
Information for the IBD service		
Question number	Data item	Help notes
PE1.5	There is written information for patients with IBD on whom to contact in the event of a relapse.	Select 'yes' if you have this information included in a service information leaflet
Rapid access to advice		
Question number	Data item	Help notes
PE2.2	Patients have access to contact an IBD Specialist via telephone.	IBD Standard A11: All IBD patients who have a concern or questions about their IBD should have access to a dedicated telephone service (IBD Helpline) that is either answered or has an answerphone facility providing a response by the end of the next working day.
PE2.5	Patients who contact the service via telephone or email are answered within 48 hours by an IBD specialist	IBD Standard A11: All IBD patients who have a concern or questions about their IBD should have access to a dedicated telephone service (IBD Helpline) that is either answered or has an answerphone facility providing a response by the end of the next working day.
Provision of information and supporting patients to exercise choice between treatments		
Question number	Data item	Help notes
PE3.2	Written information about IBD and range of treatments (eg CICRA booklets) is provided to patients as part of the consultation, to support patient's decisions where required	Crohn's NICE guidance 2012: Evidence based written information tailored to the patient's needs.
PE3.6	Access to a translator is available at all consultations if required	Crohn's NICE guidance 2012: Evidence based written information tailored to the patient's needs.

Involvement of patients in service improvement		
Question number	Data item	Help notes
PE4.1	One of the following means of assessing a patients and carers experience is used: a) an annual survey of a significant number of patients b) the IBD service subscribes to 'patient opinion' or a similar feedback service c) comment cards are given to randomly sampled outpatient and inpatients	Patient opinion (www.patientopinion.org.uk) is a web based service where patients can give feedback about a service
PE4.2	The service has an IBD patient panel or similar patient involvement group through which patients discuss with health professionals how the service might be improved	Eg open forum is a patient education event, often involving local patient groups. These may take the form of talks about topics of interest or Q7A sessions with specialists
PE4.3	The service can utilise patient opinions through individual patient or carer representatives at meetings	This can include an open forum or open evening as well as formal groups
Education of patients		
PE5.2	Regular education opportunities (eg specialist nursing visits) are available for all IBD patients and their families as individuals or in groups, to enable them to understand their illness and the options for treatment and to support them in managing their own care	Answer 'yes' if you offer regular group education sessions or routinely offer patients the chance to discuss their condition in detail (this should reflect more than the routine education that takes place during a standard consultation).

Section 3: Clinical Quality		
The IBD team		
Question number	Data item	Help notes
CQ1.2	The IBD service is routinely supported by a radiologist with a special interest in paediatric gastroenterology	Answer yes if you have regular radiology support for an IBD MDT or named radiologist(s) with a particular interest in gastroenterology who is routinely available to discuss individual patients
CQ1.3	The IBD service is routinely supported by a histopathologist with an interest in paediatric gastroenterology	They attend MDT meetings; named individual to discuss individual patients
CQ1.6	There is defined access to a paediatric ophthalmologist	Eg They attend the MDT meeting; named individual to discuss individual patients
CQ1.7	The IBD service has 0.5WTE administrative support per 250,000 population the IBD Service	Administrative support for IBD team eg for MDT meetings, data entry and audit This does not include routine secretarial support provided for consultants or IBD nurses

Inpatient monitoring		
Question number	Data item	Help notes
CQ2.1	>50% of IBD patients have all of the following undertaken on admission to hospital: weight, nutritional risk assessment eg STAMP or PYMS score	<ul style="list-style-type: none"> - If you have participated in the IBD inpatient care audit, you can use your raw data export from the web tool (or previous site report) to help you answer this question. - The assessment/screening tool used should ideally address: any unintentional weight loss, BMI, appetite, ability to eat/swallow, hydration, any additional stress factors (surgery/disease process) - Applies also to CQ2.4, CQ2.7 and CQ2.10
CQ2.3	>40% IBD patients, with diarrhoea, have a stool sample sent for Standard Stool Culture and Clostridium difficile on admission	<ul style="list-style-type: none"> - If you have participated in the IBD inpatient care audit, you can use your raw data export from the web tool (or previous site report) to help you answer this question. - Patients where stool samples were sent within the 7 days prior to admission can be included - Applies also to CQ2.6, CQ2.9 and CQ2.12
Arrangements for use of immunosuppressives		
Question number	Data item	Help notes
CQ6.9	Patients receiving biological therapy are reviewed at least 3 monthly in person to monitor efficacy and adverse events (either locally or as part of a shared care agreement with a tertiary centre)	Crohn's NICE guidance 2012: People should have their disease reassessed to determine whether on-going treatment is still clinically appropriate
CQ6.11	If monitoring is shared between services, there are clear written agreements on who has responsibility for the taking and monitoring of blood tests and prescribing azathioprine, mercaptopurine, or methotrexate. There is a clear guidance written guidance on the action required if white cell counts are low	Select not applicable only if monitoring is not shared between services.
Surgery for IBD		
Question number	Data item	Help notes
CQ7.1	Consent of patients undergoing surgery is fully informed and supported by written information on the risks and benefits	<p>Throughout section 7, chose only select not applicable (NA) if no IBD surgery is undertaken at your site. For CQ7.4 and CQ7.11 select 'NA' if pouch surgery is not undertaken at your site.</p> <p>CQ7.1 - The method of consent and discussion that occurred with patient must be recorded in notes.</p>

Inpatient facilities		
CQ8.5	The toilets have floor to ceiling partitions, full height doors and good ventilation, segregated	IBD Standard A3: To provide privacy for patients, ward toilets should have floor to ceiling partitions, full height doors and good ventilation to minimise embarrassment
CQ8.6	There is at least one toilet per 4 patients	IBD Standard A3: Wards for IBD patients should have a minimum of one easily-accessible toilet per three beds
CQ8.7	There is one toilet per 3 IBD patients	IBD Standard A3: Wards for IBD patients should have a minimum of one easily-accessible toilet per three beds
Section 4: Organisation and choice of care		
Outpatient care		
Question number	Data item	Help notes
OC3.5	There is a scheduled annual review of IBD patients available	Annual review: surveillance requirements, review medication, risk of osteoporosis, education updates
Transitional care		
OC4.1	There is a transitional care service within the Trust/Health Board for young people to support their transfer to adult services by 18-19 years (locally or as part of a shared care agreement with a tertiary centre)	Crohn's NICE guidance 2012: Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people. Diagnosis and management should be reviewed throughout the transition process and there should be clarity about who is the lead clinician to ensure continuity of care
Section 5: Research, education and audit		
Training and education		
Question number	Data item	Help notes
RE3.3	Advanced nursing practitioners within the IBD team have a regular, multidisciplinary training schedule. Attendance is audited and protected time for training is provided	Only select not applicable the IBD service has no IBD nurse provision
Service development		
RE5.3	The annual review is attended by a multidisciplinary team of relevant professionals and there is a reflection on the service either locally or as part of a shared care agreement with a tertiary centre	Only select not applicable if you do not undertake an annual review of your service
RE5.4	An action plan is produced as a result of the annual service review and achievement of the actions is monitored	Only select not applicable if you do not undertake an annual review of your service