

Organisational audit - round 4

Paediatric services - audit tool *VERSION 2*

Section 1: Demographics

DEM 1.1	How many IBD patients does your service manage?	
DEM 1.2	Is this figure: an estimate (enter 'e') or from a database/register (enter 'd')?	
DEM 1.3	Of these IBD patients, how many have ulcerative colitis?	
DEM 1.4	Of these IBD patients, how many have Crohn's disease?	
DEM 1.5	Of these IBD patients, how many have IBD-unspecified?	
DEM 1.6	How many new IBD patients have you seen in the last 12 months?	
DEM 1.7	Is this figure: an estimate (enter 'e') or from a database/register (enter 'd')?	
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)	
DEM 1.9	How many of these patients were readmitted within 30 days of discharge? (with LOS >24hrs)	
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)	
DEM 1.11	How many of these patients were readmitted within 30 days of discharge? (with LOS >24hrs)	
DEM 1.12	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 ulcerative colitis? (with LOS >24hrs)	
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? (with LOS >24hrs)	
DEM 1.14	Do surgeons perform ileo-anal surgery on site?	
DEM 1.15	How many ileo-anal pouch operations were performed between 1 January and 31 December 2013?	
DEM 1.16	Were the majority of these ileo-anal pouch operations carried out by a paediatric surgeon in conjunction with an adult colorectal surgeon?	
DEM 1.17	How many WTE paediatric gastroenterologists are there on site?	
DEM 1.18	How many general paediatricians with an interest in gastroenterology are there on site?	
DEM 1.19	How many WTE paediatric colorectal surgeons or surgeons with suitable paediatric experience are there on site?	
DEM 1.20	How many WTE paediatric IBD nurse specialists or IBD/GI nurse specialist with suitable paediatric experience are there on site?	
DEM 1.21	How many WTE stoma nurses are there on site?	
DEM 1.22	How many WTE paediatric dietitians or dietitians with suitable paediatric experience (including the use of exclusive enteral feeding) are allocated to gastroenterology?	
DEM 1.23	How many WTE administrators are attached to the IBD team?	
DEM 1.24	Is there a named paediatric histopathologist with an interest in gastroenterology attached to the IBD team?	
DEM 1.25	Is there a named paediatric radiologist or radiologist with suitable paediatric experience (performing and reporting), with an interest in gastroenterology attached to the IBD team?	
DEM 1.26	How many patients with Crohn's disease were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	

DEM 1.27	How many patients with ulcerative colitis were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	
DEM 1.28	How many patients with IBD-unspecified were newly-started on Infliximab between 1 January and 31 December 2013 (include patients of any age)?	
DEM 1.29	How many patients with Crohn's disease were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	
DEM 1.30	How many patients with ulcerative colitis were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	
DEM 1.31	How many patients with IBD-unspecified were newly-started on Adalimumab between 1 January and 31 December 2013 (include patients of any age)?	
DEM 1.32	Are the figures in DEM 26 to DEM 31 an estimate (enter 'e') or from a database/register (enter 'd')?	
DEM 1.33	How many patients admitted primarily for treatment of their IBD between 1 January and 31 December 2013, died during that admission	

Section 2: Patient experience			
Information on the IBD service		Yes	No
PE1.1	Patients and carers are advised about their follow up arrangements on discharge from hospital or at initial clinic visit.	<input type="radio"/>	<input type="radio"/>
PE1.2	Patients and carers are provided with written information on discharge or initial clinic visit, on the service for children with IBD, including how to access IBD services and arrangements for follow up	<input type="radio"/>	<input type="radio"/>
PE1.3	IBD patients and carers are given the opportunity to provide feedback on their care	<input type="radio"/>	<input type="radio"/>
PE1.4	There has been reporting, followed by action plan and changes, carried out as a result of the patient's feedback on their care within the last year	<input type="radio"/>	<input type="radio"/>
PE1.5	There is clear guidance on how patients can seek a second opinion if they are unhappy with their care / need advice	<input type="radio"/>	<input type="radio"/>
Rapid access to specialist advice		Yes	No
PE2.1	Patients and carers are provided with written information on how to access specialist IBD advice eg a direct line to call in the event of a relapse	<input type="radio"/>	<input type="radio"/>
PE2.2	Patients and carers have access to contact an IBD specialist by a telephone with an answer machine	<input type="radio"/>	<input type="radio"/>
PE2.3	There is usually access to a face-to-face review by a specialist (nurse/ medical) within 2 weeks	<input type="radio"/>	<input type="radio"/>
PE2.4	Patients and carers are able to contact an IBD specialist an email service	<input type="radio"/>	<input type="radio"/>
PE2.5	Contacts from patients and carers are responded to answered within 48 hours by an IBD specialist	<input type="radio"/>	<input type="radio"/>
PE2.6	Patients and carers are provided with the name and number of a paediatric IBD specialist (specialist nurse or consultant) who can be contacted for advice.	<input type="radio"/>	<input type="radio"/>
PE2.7	Specialist review is usually access to a face-to-face review by a specialist (nurse/ medic) available for relapsed patients within 7 days	<input type="radio"/>	<input type="radio"/>
PE2.8	Patients have access to an IBD specialist via a drop in clinic	<input type="radio"/>	<input type="radio"/>
PE2.9	Patients and carers are provided with a choice of ways to contact an IBD specialist, to find specialist IBD advice including: the name and number of a paediatric IBD specialist (specialist nurse or medic), a telephone with an answer machine (answered within 48 hours), an email service (answered within 48 hours) or a manned telephone service	<input type="radio"/>	<input type="radio"/>
PE2.10	A face-to-face review by a specialist (nurse/ medic) is available for all relapsed patients within 5 working days.	<input type="radio"/>	<input type="radio"/>

Provision of information and supporting patients to exercise choice between treatments		Yes	No
PE3.1	Written information about IBD and range of treatments (eg CICRA booklets) is made available to all patients.	<input type="radio"/>	<input type="radio"/>
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.	<input type="radio"/>	<input type="radio"/>
PE3.3	Information is available that is appropriate to the age, understanding and communication needs of the patients attending the IBD service.	<input type="radio"/>	<input type="radio"/>
PE3.4	Written and/or audio-visual information about IBD, a range of treatments and practical issues of living with IBD are provided to patients/carers as part of the consultation, when required.	<input type="radio"/>	<input type="radio"/>
PE3.5	Patients and carers receive clear explanations supported by written information about the benefits of significant alternative treatment options (eg between drug and dietary therapy for Crohn's disease, between steroids or aminosalicylates [5ASA] for inducing remission in ulcerative colitis, between rescue medical therapy and surgery during an acute severe relapse.)	<input type="radio"/>	<input type="radio"/>
PE3.6	Access to a translator is available at all consultations if required	<input type="radio"/>	<input type="radio"/>
PE3.7	Newly-diagnosed patients are provided with a written care plan	<input type="radio"/>	<input type="radio"/>
PE3.8	A selection of written information is available for patients and carers in languages other than English, reflecting the major ethnic minority groups among patients.	<input type="radio"/>	<input type="radio"/>
PE3.9	The IBD service has a formally expressed policy that patients and carers are actively involved in management decisions about care with access to all members of the multidisciplinary team. Implementation of this policy is reviewed in IBD team meetings.	<input type="radio"/>	<input type="radio"/>
Involvement of patients in service improvement		Yes	No
PE4.1	One of the following means of assessing 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 similar feedback service or c) comment cards are given to randomly sampled outpatients and inpatients.	<input type="radio"/>	<input type="radio"/>
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	<input type="radio"/>	<input type="radio"/>
PE4.3	The service can utilise patient opinions through individual patient or carer representatives at meetings	<input type="radio"/>	<input type="radio"/>
PE4.4	Patients and carers are involved in service planning and improvements	<input type="radio"/>	<input type="radio"/>
Education of patients		Yes	No
PE5.1	Newly-diagnosed patients are offered one-to-one education with an IBD nurse or dietitian	<input type="radio"/>	<input type="radio"/>
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	<input type="radio"/>	<input type="radio"/>
PE5.3	The IBD service participates in an open forum meeting which meets at least annually.	<input type="radio"/>	<input type="radio"/>
Information and support for patient organisations		Yes	No
PE6.1	Written information is made available to all new patients, providing information about relevant patient organisations	<input type="radio"/>	<input type="radio"/>
PE6.2	All IBD patients and carers are provided with information about their local patient support groups	<input type="radio"/>	<input type="radio"/>
PE6.3	There is regular contact and support from the IBD team about educational activities for patients eg Crohn's and Colitis UK (NACC) group meetings, NACC or CICRA paediatric events, IA (The Ileostomy and Internal Pouch Support Group) meetings, local pouch support groups either locally or a part of a regional network	<input type="radio"/>	<input type="radio"/>

Section 3: Clinical quality		
The IBD team		Yes No
CQ1.1	The IBD service has a named clinical lead. There is a consultant paediatric gastroenterologist or a designated paediatrician with an interest in IBD working with an adult physician with interest in young people, within a shared clinical network.	<input type="radio"/> <input type="radio"/>
CQ1.2	The IBD service is routinely supported by a radiologist with a special interest in IBD or paediatric gastroenterology	<input type="radio"/> <input type="radio"/>
CQ1.3	The IBD service is routinely supported by a histopathologist with an interest in paediatric gastroenterology	<input type="radio"/> <input type="radio"/>
CQ1.4	There are the following: stoma nurse, dietitian, consultant colorectal surgeon, with appropriate paediatric training and expertise, available to all IBD paediatric patients	<input type="radio"/> <input type="radio"/>
CQ1.5	The IBD service is routinely supported by a pharmacist with a special interest in IBD or paediatric gastroenterology	<input type="radio"/> <input type="radio"/>
CQ1.6	There is defined access to a paediatric ophthalmologist	<input type="radio"/> <input type="radio"/>
CQ1.7	The local IBD team or shared care team has 0.5WTE administrative support, per 250,000 population the IBD service	<input type="radio"/> <input type="radio"/>
CQ1.8	There is defined access to a paediatric rheumatologist	<input type="radio"/> <input type="radio"/>
CQ1.9	The local IBD team or shared care team has a minimum of 2 WTE consultant paediatric gastroenterologists, 2 WTE consultant surgeons with appropriate colorectal expertise, 1.5 WTE paediatric nurse specialists with IBD expertise, 1.5 WTE stoma nurse specialists with paediatric expertise and 0.5 WTE paediatric dietitians per 250,000 population	<input type="radio"/> <input type="radio"/>
Inpatient monitoring		Yes No
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	<input type="radio"/> <input type="radio"/>
CQ2.2	>40% IBD patients have regular stool chart documented during admission	<input type="radio"/> <input type="radio"/>
CQ2.3	>40% IBD patients, with diarrhoea, have a stool sample sent for standard stool culture and clostridium difficile on admission.	<input type="radio"/> <input type="radio"/>
CQ2.4	>60% of IBD patients have all of the following undertaken on admission to hospital: weight, nutritional risk assessment eg STAMP or PYMS score	<input type="radio"/> <input type="radio"/>
CQ2.5	>50% of IBD patients have regular stool chart documented during admission	<input type="radio"/> <input type="radio"/>
CQ2.6	>50% IBD patients with diarrhoea, have a stool sample sent for standard stool culture and clostridium difficile on admission	<input type="radio"/> <input type="radio"/>
CQ2.7	>80% of IBD patients have all of the following undertaken on admission to hospital: weight, nutritional risk assessment eg STAMP or PYMS score	<input type="radio"/> <input type="radio"/>
CQ2.8	>60% of IBD patients have regular stool chart documented during admission.	<input type="radio"/> <input type="radio"/>
CQ2.9	>60% IBD patients with diarrhoea, have a stool sample sent for standard stool culture and clostridium difficile on admission	<input type="radio"/> <input type="radio"/>
CQ2.10	>90% of IBD patients have all of the following undertaken on admission to hospital: weight, nutritional risk assessment eg STAMP or PYMS score	<input type="radio"/> <input type="radio"/>
CQ2.11	>70% of IBD patients have regular stool chart documented during admission	<input type="radio"/> <input type="radio"/>
CQ2.12	>70% IBD patients with diarrhoea, have a stool sample sent for standard stool culture and clostridium difficile on admission	<input type="radio"/> <input type="radio"/>
Mental health services		Yes No
CQ3.1	Referrals can be made to local CAMHS (Child and Adolescent Mental Health Services) teams for psychiatric evaluation, but there is little/no input into the IBD teams or on the inpatient wards	<input type="radio"/> <input type="radio"/>

CQ3.2	IBD patients can be referred by the IBD service for psychological or counselling input, via the local CAMHS teams.	<input type="radio"/>	<input type="radio"/>
CQ3.3	There is a psychology outpatient clinic or a psychiatric liaison service available within the acute service for all IBD patients (inpatient and outpatient) or as part of a shared care agreement with a tertiary centre.	<input type="radio"/>	<input type="radio"/>
CQ3.4	Referrals for psychological support for families and carers are available	<input type="radio"/>	<input type="radio"/>
CQ3.5	Psychology or liaison psychiatry are an integral part of care for all paediatric IBD patients or a paediatric psychologist works closely with team (available locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
Multidisciplinary working		Yes	No
CQ4.1	There are regular multidisciplinary meetings in which management of individual patients and complex IBD cases can be discussed (either paediatric IBD meetings or jointly with adult IBD services locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
CQ4.2	There is a defined arrangement for joint medical/surgical discussion with patients whose clinical condition will not wait for the next available clinic	<input type="radio"/>	<input type="radio"/>
CQ4.3	There are joint or parallel clinics for patients requiring joint paediatric and surgical care, which take place at least 4 times per year.	<input type="radio"/>	<input type="radio"/>
CQ4.4	IBD patients under paediatric or surgical care can be seen urgently in clinic by paediatric and/or surgical team (either locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
CQ4.5	There is a multidisciplinary attendance at IBD team meetings, including paediatric gastroenterologist (or paediatrician with interest in IBD), paediatric surgeon, paediatric specialist nurse, (either locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
CQ4.6	The IBD team meetings occur at least every 2 weeks, have an attendance register and are minuted (either locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
CQ4.7	There is attendance at multidisciplinary team meetings by a gastroenterology dietitian	<input type="radio"/>	<input type="radio"/>
CQ4.8	There are joint or parallel clinics for patients requiring joint paediatric and surgical care (either locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
CQ4.9	Decisions from the IBD team meeting are documented in the patient notes and fed back to the patient and carers	<input type="radio"/>	<input type="radio"/>
CQ4.10	There is attendance at multidisciplinary team meetings by a pharmacist	<input type="radio"/>	<input type="radio"/>
CQ4.11	There are joint or parallel clinics for patients requiring joint paediatric and surgical care, which take place which take place at least weekly (either locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
Access to nutritional support and therapy		Yes	No
CQ5.1	>50% IBD patients (patients with Crohn's and acute severe ulcerative colitis) are reviewed by a paediatric dietitian (or gastroenterology dietitian with suitable paediatric experience) during an inpatient stay	<input type="radio"/>	<input type="radio"/>
CQ5.2	IBD patients can be referred to a paediatric dietitian experienced in the dietary management of IBD (either locally or as part of a shared care agreement with a tertiary centre) experienced in the dietary management of IBD for general dietary advice and nutritional support.	<input type="radio"/>	<input type="radio"/>
CQ5.3	There is a multidisciplinary nutrition team available to IBD inpatients	<input type="radio"/>	<input type="radio"/>
CQ5.4	>69% IBD patients (with Crohn's disease, acute colitis or newly-diagnosed IBD) are reviewed by a paediatric dietitian during an inpatient stay	<input type="radio"/>	<input type="radio"/>

CQ5.5	The multidisciplinary nutrition team is made up of paediatric dietitians, specialist paediatric nutrition support nurse, consultant paediatric gastroenterologist and or a consultant paediatric (or appropriate adult) colorectal surgeon (either locally or as part of a shared care agreement with a tertiary centre).	<input type="radio"/>	<input type="radio"/>
CQ5.6	>79% IBD patients (with Crohn's disease, acute colitis or newly-diagnosed IBD) have a dietetic review by a paediatric dietitian during an inpatient stay	<input type="radio"/>	<input type="radio"/>
CQ5.7	Exclusive enteral nutrition therapy as a primary treatment is available to all patients with Crohn's disease (either locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
CQ5.8	Information given to all patients newly-diagnosed with Crohn's disease and their carers (includes nutritional advice)	<input type="radio"/>	<input type="radio"/>
CQ5.9	All newly-diagnosed IBD patients are routinely screened for malnutrition	<input type="radio"/>	<input type="radio"/>
CQ5.10	All IBD patients are reviewed by the multidisciplinary nutrition team early in their admission	<input type="radio"/>	<input type="radio"/>
CQ5.11	>90% IBD patients (with Crohn's disease, acute colitis or newly-diagnosed IBD) have a dietetic review by a paediatric dietitian during an inpatient stay	<input type="radio"/>	<input type="radio"/>
CQ5.12	Regular assessment (minimum 4 monthly) occurs to ensure that nutritional intake is enough to facilitate normal growth and pubertal development	<input type="radio"/>	<input type="radio"/>
CQ5.13	Clear pathways are in place to provide home enteral nutrition support and monitoring. Access to home parenteral nutrition is via an established link with a national HPN provider.	<input type="radio"/>	<input type="radio"/>
Arrangements for use of immunosuppressives		Yes	No
CQ6.1	There are written and updated local or regional network protocols for the administration of immunosuppressives and biological therapies	<input type="radio"/>	<input type="radio"/>
CQ6.2	Prior to starting biological therapies screening for tuberculosis and consideration of a vaccination programme is carried out	<input type="radio"/>	<input type="radio"/>
CQ6.3	All patients and parents are counselled about the risk of malignancy and sepsis prior to starting immunosuppressive therapy and informed consent is obtained and documented in the notes	<input type="radio"/>	<input type="radio"/>
CQ6.4	Local or regional network protocols for the administration of biological therapies include details on the taking of fully informed consent, pre-infusion assessment and actions for pre-treatment, actions for infusion reactions and accelerated infusions	<input type="radio"/>	<input type="radio"/>
CQ6.5	Patients on immunosuppressive treatment have a white blood count measured according to nationally agreed guidelines at least 3 monthly	<input type="radio"/>	<input type="radio"/>
CQ6.6	Clinicians involved in the management of patients on immunosuppressants have access to a pharmacist with specialist knowledge / interest	<input type="radio"/>	<input type="radio"/>
CQ6.7	There is clear written guidance for families and those involved in shared care (secondary care/GPs) on action to be taken, if white cell counts are below normal range	<input type="radio"/>	NA
CQ6.8	The decision to start anti-TNF therapy is usually made after discussion in a multidisciplinary team meeting (either locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
CQ6.9	Patients receiving biological therapy are reviewed at least 3 monthly in person, to monitor efficacy and adverse effects (either locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
CQ6.10	A local patient information sheet which includes advice on action if adverse events occur is given to all patients and carers on any type of immunosuppressive treatment.	<input type="radio"/>	<input type="radio"/>
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 on the action required if white cell counts are low	<input type="radio"/>	NA

CQ6.12	IBD patients on either immunomodulator or biological therapy are subject to regular audits for outcomes (either locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
CQ6.13	When monitoring treatment for patients on immunosuppressives, the most convenient place (within primary, secondary or tertiary care) for the patient is accommodated where possible	<input type="radio"/>	<input type="radio"/>
CQ6.14	Patients receiving immunomodulators and biological therapies are provided with written information about side effects and the required monitoring	<input type="radio"/>	<input type="radio"/>
CQ6.15	Patients have a choice of appointment times for anti-TNF infusions (ie morning, afternoon, or evening)	<input type="radio"/>	<input type="radio"/>
CQ6.16	IBD patients on either immunomodulator or biological therapy are subject to at least yearly audit for outcomes	<input type="radio"/>	<input type="radio"/>
Surgery for IBD		Yes	No
CQ7.1	Consent of patients undergoing surgery is fully informed and supported by written information on the risks and benefits	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.2	Paediatric gastroenterology and appropriate colorectal surgical facilities are located on the same site or there is a shared care agreement with a tertiary centre with these facilities	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.3	Consent is routinely taken by the surgeon who will be carrying out the operation or who has carried out the procedure before. Patients have access to independent advocates if required. Patients and parents are fully involved in any decisions and are offered written and/or audio visual information	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.4	The outcome of all patients undergoing ileal pouch surgery is audited on the Association of Coloproctology of Great Britain and Ireland (ACPGBI) ileal pouch registry	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.5	Decisions to undertake surgical procedures are undertaken after joint discussion between paediatric / medical / surgical and other MDT members in a formal MDT meeting	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.6	Appropriate postoperative ward facilities exist for the management of children and adolescents undergoing IBD surgery	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.7	There is a gastrointestinal pathologist assessment before surgery, which may involve referral of cases to a nationally recognised expert in the diagnosis and differential diagnosis of chronic inflammatory bowel disease. This is available locally or as part of a shared care agreement with a tertiary centre.	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.8	Anaesthesia for IBD surgery is carried out routinely by accredited paediatric anaesthetists	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.9	One consultant surgeon with dedicated paediatric IBD experience, is the nominated lead for paediatric IBD surgery within the Trust/Health Board. They support decision-making and / or surgery for complex IBD cases	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.10	There are facilities and trained surgeons to offer laparoscopic / laparoscopically-assisted surgery where possible and appropriate	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
CQ7.11	Pouch failure (and salvage) is managed in or routinely referred to, an agreed regional specialist unit, with appropriate expertise in re-operative pouch surgery	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA

CQ7.12	There is annual review of IBD surgical service with review of activity and mortality and morbidity. There is an action plan which is regularly reviewed (at least yearly) for implementation. There is a formal regular governance process to review surgical morbidity and mortality within the Trust/Health Board/Network, including review and/or audit of postoperative complications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	NA
Inpatient facilities		Yes	No		
CQ8.1	Adolescents (patients aged 16-19) are placed in the most suitable bed for the individual patient	<input type="radio"/>	<input type="radio"/>		
CQ8.2	More than one toilet available per bay of patients. Facilities are available for change and disposal of stoma appliances	<input type="radio"/>	<input type="radio"/>		
CQ8.3	Paediatric gastroenterology patients are routinely managed in a specialist ward (eg specialist dedicated ward)	<input type="radio"/>	<input type="radio"/>		
CQ8.4	There is access to urgent paediatric assessment 24 hours a day. The hospital has a paediatric intensive care unit (PICU) or clear referral pathways for urgent transfer to a specialist intensive bed	<input type="radio"/>	<input type="radio"/>		
CQ8.5	All toilets have floor to ceiling partitions, full height doors and good ventilation and are segregated	<input type="radio"/>	<input type="radio"/>		
CQ8.6	There is at least 1 toilet per 4 patients	<input type="radio"/>	<input type="radio"/>		
CQ8.7	There is a least one toilet per 3 IBD patients	<input type="radio"/>	<input type="radio"/>		
Access to diagnostic services		Yes	No		
CQ9.1	Endoscopy takes place in a child friendly and suitably equipped environment with appropriate paediatric anaesthetic sessions and facilities, locally or as part of a shared care agreement with a tertiary centre. If endoscopy is carried out by an adult endoscopist, they work in accordance to local paediatric network guidelines.	<input type="radio"/>	<input type="radio"/>		
CQ9.2	Radiological investigations are performed in a setting suitable for children, by staff trained in performing and reporting them for children	<input type="radio"/>	<input type="radio"/>		
CQ9.3	All histological reports are available within 5 working days, locally or as part of a shared care agreement with a tertiary centre.	<input type="radio"/>	<input type="radio"/>		
CQ9.4	There is access to ultrasound/CT/contrast studies for inpatients within 24 hours	<input type="radio"/>	<input type="radio"/>		
CQ9.5	There is a clear process on how to access endoscopy urgently, so that patients admitted with relapse are scoped within 72 hours of admission, with clear guidelines/ policy available to staff.	<input type="radio"/>	<input type="radio"/>		
CQ9.6	Urgent histology biopsies can be reported within 2 days locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>		
CQ9.7	Drainage of an abscess is carried out by either interventional radiology or surgical means, locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>		
CQ9.8	X-ray reports of presence of toxic megacolon (transverse colon >4cm in children under 10 years and >6cm in children over 10 years) are documented in the notes or on radiology report. Documentation by most senior member of team who comments on initial X-ray	<input type="radio"/>	<input type="radio"/>		
CQ9.9	PUCAI (paediatric UC disease activity index score) is used at day 3 and 5 for assessment of patients with acute severe ulcerative colitis	<input type="radio"/>	<input type="radio"/>		
CQ9.10	As an alternative to investigations with higher radiation there is access to small bowel investigations such as MRI or abdominal ultrasound (carried out by a skilled practitioner)	<input type="radio"/>	<input type="radio"/>		
CQ9.11	Outpatient access to ultrasound/CT/contrast studies and endoscopic assessment within 4 weeks maximum, or in more urgent situations, within 24 hours either locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>		

CQ9.12	There is a consultant radiologist(s) who primarily reports all paediatric gastrointestinal radiology in the hospital or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>
CQ9.13	Histology reporting times and outpatient waiting times for IBD patients for CT/MR and endoscopy have been recently audited	<input type="radio"/>	<input type="radio"/>

Section 4: Organisation and choice of care			
Inpatient care		Yes	No
OC1.1	>30%of IBD patients are seen within 24 hours of admission, by a paediatric IBD specialist or a paediatrician with interest in gastroenterology working in conjunction with a paediatric IBD specialist, who is available for immediate telephone advice.	<input type="radio"/>	<input type="radio"/>
OC1.2	There is an acute pain management team available on site	<input type="radio"/>	<input type="radio"/>
OC1.3	>50% of patients, who are receiving steroids on discharge from hospital, are placed on a steroid reduction programme and consideration has been given to prescribing bone protection agents	<input type="radio"/>	<input type="radio"/>
OC1.4	>50%of IBD patients are seen within 24 hours of admission, by a paediatric IBD specialist or a paediatrician with interest in gastroenterology working in conjunction with a paediatric IBD specialist, who is available for immediate telephone advice	<input type="radio"/>	<input type="radio"/>
OC1.5	A pharmacist is available to carry out inpatient drug reviews of IBD patients	<input type="radio"/>	<input type="radio"/>
OC1.6	The Trust/Health Board has guidelines for the management of acute severe ulcerative colitis	<input type="radio"/>	<input type="radio"/>
OC1.7	There are multidisciplinary ward rounds or case discussion which include a pharmacist and dietitian as appropriate (locally or as part of a shared care agreement with a tertiary centre)	<input type="radio"/>	<input type="radio"/>
OC1.8	Recording of pain scores is carried out at regular intervals	<input type="radio"/>	<input type="radio"/>
OC1.9	There is a defined arrangement for admitting IBD patients to a gastroenterology ward or on a named surgical ward, during admission	<input type="radio"/>	<input type="radio"/>
OC1.10	>60 % of patients who are receiving steroids on discharge from hospital, are placed on a steroid reduction programme and consideration has been given to prescribing bone protection agents	<input type="radio"/>	<input type="radio"/>
OC1.11	>70% of IBD patients are seen within 24 hours of admission, by a paediatric IBD specialist or a paediatrician with interest in gastroenterology working in conjunction with a paediatric IBD specialist, who is available for immediate telephone advice	<input type="radio"/>	<input type="radio"/>
OC1.12	There are multidisciplinary ward rounds / case discussion of IBD inpatients at least once a week	<input type="radio"/>	<input type="radio"/>
OC1.13	It is usual practice to refer an inpatient with severe pain (measured by pain scores) to the acute pain management team	<input type="radio"/>	<input type="radio"/>
OC1.14	There are multidisciplinary care ward rounds/case discussion which includes a dietitian	<input type="radio"/>	<input type="radio"/>
OC1.15	>80 % of patients who are receiving steroids on discharge from hospital, are placed on a steroid reduction programme and consideration has been given to prescribing bone protection agents	<input type="radio"/>	<input type="radio"/>
OC1.16	All patients under 16 are under the care of a consultant paediatric gastroenterologist or a consultant paediatrician with expertise in paediatric IBD (working in partnership with adult gastroenterology and /or colorectal surgical teams) within 24 hours of admission	<input type="radio"/>	<input type="radio"/>
OC1.17	The paediatric gastroenterology service or paediatric ward has a dedicated paediatric pharmacist with specialist interest and knowledge of IBD, including biological therapies	<input type="radio"/>	<input type="radio"/>

OC1.18	All patients (and carers) due to have or who do have a stoma, can be seen by a stoma nurse during their admission if required	<input type="radio"/>	<input type="radio"/>
OC1.19	Heparin is provided on an individual patient basis, based on risk and benefits and decided by a senior physician or paediatrician	<input type="radio"/>	<input type="radio"/>
OC1.20	There are multidisciplinary care ward rounds/case discussion which includes a pharmacist	<input type="radio"/>	<input type="radio"/>
OC1.21	All patients with patient controlled analgesia are reviewed daily by the acute pain management team	<input type="radio"/>	<input type="radio"/>
OC1.22	All patients with regular high pain scores are reviewed by the acute pain management team	<input type="radio"/>	<input type="radio"/>
OC1.23	>90% of patients who are receiving steroids on discharge from hospital, are placed on a steroid reduction programme and consideration has been given to prescribing bone protection agents	<input type="radio"/>	<input type="radio"/>
Referral of suspected IBD patients		Yes	No
OC2.1	There is an agreed referral pathway between secondary/primary and tertiary care for new or suspected IBD patients to be seen urgently in OPD	<input type="radio"/>	<input type="radio"/>
OC2.2	For initial investigation and treatment children and adolescents should be referred to a paediatric gastroenterology service which is part of a paediatric gastroenterology clinical network	<input type="radio"/>	<input type="radio"/>
OC2.3	Follow up is shared with the referring district hospital and a paediatrician with an interest in gastroenterology as part of the clinical network	<input type="radio"/>	<input type="radio"/>
OC2.4	Most urgent new IBD referrals are seen in clinic within 2 weeks	<input type="radio"/>	<input type="radio"/>
OC2.5	For the physically mature patient who has completed their growth is emotionally mature and without psychological or educational problems, investigations may be undertaken locally by the adult service. This should be by a gastroenterologist experienced in the management of adolescents with IBD in discussion with a paediatrician with appropriate expertise in gastroenterology	<input type="radio"/>	<input type="radio"/>
OC2.6	All urgent new referrals are seen within a week	<input type="radio"/>	<input type="radio"/>
OC2.7	Guidance has been developed to guide GP's and secondary care in the referral and identification of symptomatic patients in whom IBD is suspected and when a review of patients with unresponsive, atypical or troublesome abdominal symptoms should occur	<input type="radio"/>	<input type="radio"/>
OC2.8	There has been an internal audit of the time from referral to being seen in the last 12 months	<input type="radio"/>	<input type="radio"/>
Outpatient care		Yes	No
OC3.1	The following are usually documented for all patients: Number of liquid stools per day, passage of blood, abdominal pain and assessment of growth (height and weight) and pubertal growth (Tanner staging) where required.	<input type="radio"/>	<input type="radio"/>
OC3.2	The following are documented, throughout disease course: Number of liquid stools per day, abdominal pain or mass, general well-being, psychological concerns, weight loss, assessment of growth (height and weight). Pubertal growth (Tanner staging) and smoking status is assessed in patients over 10 years.	<input type="radio"/>	<input type="radio"/>
OC3.3	Patients receiving steroids are identified, including duration of continual treatment (especially any patients receiving treatment for greater than 3 months).	<input type="radio"/>	<input type="radio"/>
OC3.4	All children with ulcerative colitis who have had the disease for more than 10 years are formally identified and a surveillance plan made (with adult services)	<input type="radio"/>	<input type="radio"/>
OC3.5	There is a scheduled annual review of IBD patients available	<input type="radio"/>	<input type="radio"/>
OC3.6	Patients and carers are able to choose between hospital management in a regional centre and shared care with their local hospital. Families can choose a different option at different stages in their illness	<input type="radio"/>	<input type="radio"/>

OC3.7	Information about the shared care agreements between the acute service and primary care is given to patients	<input type="radio"/>	<input type="radio"/>
OC3.8	The criteria for annual review are agreed by the IBD team but would normally include indications for all therapies, assessment of growth & puberty, steroid exposure, review of educational and psychological issues, colorectal cancer surveillance when appropriate	<input type="radio"/>	<input type="radio"/>
OC3.9	Annual data is collected and presented on the percentage of patients who remain on steroids continuously for 3 months; these results are discussed at MDT along with those started on additional therapy (eg surgery, immunosuppressives or anti-TNFs). This is done locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>
OC3.10	IBD patients are reviewed at least annually (include any means of follow up, including hospital clinic, telephone clinic, email or postal review)	<input type="radio"/>	<input type="radio"/>
Transitional care		Yes	No
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)	<input type="radio"/>	<input type="radio"/>
OC4.2	There is an identifiable clinic (or part of a clinic) for transition of patients with IBD from paediatric to adult follow up. The clinic should include representatives from both the adult and paediatric teams (can be medical staff, specialist nurse, dietetic or other)	<input type="radio"/>	<input type="radio"/>
OC4.3	A named coordinator is responsible for the preparation and oversight of transitional care, from child to adult services (eg IBD nurse specialist) locally or as part of a shared care agreement with a tertiary centre.	<input type="radio"/>	<input type="radio"/>
OC4.4	Direct referral (not via GP) for a specialist endocrinology review, is available for concerns about growth and/or pubertal status	<input type="radio"/>	<input type="radio"/>
OC4.5	Each young person with IBD has an individual transition plan	<input type="radio"/>	<input type="radio"/>
OC4.6	Support and education is provided on lifestyle issues (eg: sexual health, smoking, alcohol, recreational drug use) in young people with IBD	<input type="radio"/>	<input type="radio"/>
Arrangements for shared care		Yes	No
OC5.1	There is an agreed referral pathway for rapid access for patients with relapse	<input type="radio"/>	<input type="radio"/>
OC5.2	Information about test results or treatment changes is shared with GPs and local hospitals in the form of electronic mail, written communication between the GP and hospital or a patient-held record	<input type="radio"/>	<input type="radio"/>
OC5.3	There are shared care pathways between specialist paediatric gastroenterology units and district general hospitals	<input type="radio"/>	<input type="radio"/>
Section 5: Research, education and audit			
Register of patients under the care of the IBD service		Yes	No
RE1.1	The IBD service has a searchable database or registry of paediatric IBD patients locally or as part of a shared care agreement with a tertiary centre.	<input type="radio"/>	<input type="radio"/>
RE1.2	The database is updated with clinical data about IBD patients receiving hospital care	<input type="radio"/>	<input type="radio"/>
RE1.3	The database is updated with patients on biological therapy	<input type="radio"/>	<input type="radio"/>
RE1.4	The database is updated with patients on all immunosuppressants (including biological therapies)	<input type="radio"/>	<input type="radio"/>
RE1.5	The database is updated with clinical data about all patients with a diagnosis of IBD	<input type="radio"/>	<input type="radio"/>
Participation in audit		Yes	No
RE2.1	The service participates in the (national) UK IBD audit either locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>
RE2.2	The service participates in the (national) UK IBD audit and results are feedback to the service. An action plan is completed	<input type="radio"/>	<input type="radio"/>

RE2.3	All inpatient deaths in IBD patients are reviewed by IBD team, an action plan formulated and action plan implementation is reviewed at least annually	<input type="radio"/>	<input type="radio"/>
RE2.4	The service participates in the (national) UK IBD audit, completes an action plan and ensures monitoring of actions or changes either locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>
RE2.5	There are mortality and morbidity meetings attended by a multidisciplinary team, to discuss any deaths and outcomes of surgery (locally or as part of a shared care agreement with a tertiary centre). These are minuted and have attendance registers	<input type="radio"/>	<input type="radio"/>
Training and education		Yes	No
RE3.1	There are education opportunities for all medical and nursing staff	<input type="radio"/>	<input type="radio"/>
RE3.2	All members of the IBD team are encouraged to participate in local and national professional education to maintain their competence and knowledge in a fast developing subspecialty. This is monitored and documented for regular CPD	<input type="radio"/>	<input type="radio"/>
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	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
Research		Yes	No
RE4.1	The IBD service is part of a clinical trials network (MCRN)	<input type="radio"/>	<input type="radio"/>
RE4.2	The IBD service has enrolled patients in an IBD trial in the last two years	<input type="radio"/>	<input type="radio"/>
RE4.3	Participation in research is supported by the service, with monetary support and/or flexible working. All members of service are encouraged to participate	<input type="radio"/>	<input type="radio"/>
Service development		Yes	No
RE5.1	An annual review of the IBD service is carried out either locally or as part of a shared care agreement with a tertiary centre	<input type="radio"/>	<input type="radio"/>
RE5.2	The IBD team has been involved in one or more clinical network arrangements or events with neighbouring IBD services, in the last year	<input type="radio"/>	<input type="radio"/>
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	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA
RE5.4	An action plan is produced as a result of the annual service review and achievement of the actions is monitored	<input type="radio"/>	<input type="radio"/>
		<input type="radio"/>	NA