## **Paediatric Organisational Audit**

### **Health Information Coding**

Responses for this section require data for the period between 1/12/13 - 30/11/14.

[Infliximab was introduced for the treatment of ulcerative colitis under the PBS arrangements on 1st December 2014]

Q1.1 to Q1.17 require ICD-10 coding data that should be sourced from your health information staff using the guide 'Health Information Data Request' available in the resources tab on the homepage

1.1. For the specified time period (above) How many multi-day separations (LOS>24 hours) total were there at your hospital for all diagnoses (not limited to IBD)?

#### Crohn's disease

- 1.2. How many multi-day separations (LOS>24 hours) were there for Crohn's disease (ICD-10 codes K50.0 Crohn's disease of small intestine, K50.1 Crohn's disease of large intestine, K50.8 Other Crohn's disease, K50.9 Crohn's disease, unspecified)?
- 1.3. What was the average length of stay for the multi-day Crohn's disease separations? (days)
- 1.4. How many were unplanned admissions?
- 1.5. How many were admitted for an elective surgical procedure?
- 1.6. How many of the multi-day Crohn's disease episodes were unplanned readmissions i.e were discharged less than 28 days previously with no intention to readmit?
- 1.7. How many of the multi-day Crohn's disease patients died during the admission?
- 1.8 How many of the multiday Crohn's disease episodes had procedure codes for:
- a. 32060-00: Restorative proctectomy
- b. 32051-00/01 Total proctocolectomy with ileo-anal anastomosis (including formation of temporary ileostomy)
- c. 32030-00/01 Rectosigmoidectomy with formation of stoma stoma -Hartmann's procedure
- d. 32039-00: Abdominoperineal proctectomy (APR)
- e. 32024-00: High anterior resection of rectum
- f. 32025-00: Low anterior resection of rectum
- g. 32026-00: Ultra low anterior resection of rectum
- h. 32047-00: Perineal proctectomy

- i. 32006-00 to -03 Left hemicolectomy with anastomosis (incl. formation of stoma)
- j. 32003-00/02 Limited excision of large intestine with anastomosis
- k. 32000-00/02 Limited excision of large intestine with formation of stoma
- I. 32003-01/03 Right hemicolectomy with anastomosis
- m. 32000-01/03 Right hemicolectomy with formation of stoma
- n. 32005-0: Extended right hemicolectomy with anastomosis
- o. 32004-0: Extended right hemicolectomy with formation of stoma
- p. 32009-00/01: Total colectomy with ileostomy
- q. 32012-00/01: Total colectomy with ileorectal anastomosis
- r. 30564: Stricture plasty of small intestine
- s. 30565: Resection of small intestine with formation of stoma
- t. 30566: Resection of small intestine with anastomosis
- 1.9. How many multi-day separations (LOS>24 hours) were there for people with an admission age <18 years at their admission date for Crohn's disease?

#### Ulcerative colitis (including indeterminate colitis)

- 1.10. How many multi-day separations (LOS>24 hours) were there for ulcerative colitis (ICD-10 codes K51.0 Ulcerative (chronic) pancolitis, K51.2 Ulcerative (chronic) proctitis, K51.3 Ulcerative (chronic) rectosigmoiditis, K51.4 Inflammatory polyps, K51.5 Left hemicolitis, K51.8 Other ulcerative colitis K51.9 Ulcerative colitis, unspecified, K52.3 indeterminate colitis)?
- 1.11. What was the average length of stay for the multi-day ulcerative colitis separations? (days)
- 1.12. How many were unplanned admissions?
- 1.13. How many were admitted for an elective surgical procedure?
- 1.14. How many of the multi-day ulcerative colitis episodes were unplanned readmissions i.e were discharged less than 28 days previously with no intention to readmit?
- 1.15. How many of the multi-day ulcerative colitis patients died during the admission?
- 1.16 How many of the multiday ulcerative colitis episodes had procedure codes for:
- a. 32060-00: Restorative proctectomy
- b. 32051-00/01 Total proctocolectomy with ileo-anal anastomosis (including formation of temporary ileostomy)

c. 32030-00/01 Rectosigmoidectomy with formation of stoma - Hartmann's Procedure d. 32039-00: Abdominoperineal proctectomy (APR) 32024-00: High anterior resection of rectum e. f. 32025-00: Low anterior resection of rectum 32026-00: Ultra low anterior resection of rectum g. h. 32047-00: Perineal proctectomy i. 32006-00 to -03 Left hemicolectomy with anastomosis (incl. formation of stoma) 32003-00/02 Limited excision of large intestine with anastomosis j. k. 32000-00/02 Limited excision of large intestine with formation of stoma Ι. 32003-01/03: Right hemicolectomy with anastomosis m. 32000-01/03: Right hemicolectomy with formation of stoma 32005-0: Extended right hemicolectomy with anastomosis n. 32004-0: Extended right hemicolectomy with formation of stoma 0. 32009-00/01: Total colectomy with ileostomy p. 32012-00/01: Total colectomy with ileorectal anastomosis q. r. 30564: Stricture plasty of small intestine 30565: Resection of small intestine with formation of stoma S. 30566: Resection of small intestine with anastomosis t. 1.17. How many multi-day separations (LOS>24 hours) were there for people with an admission age <18 years at their admission date for ulcerative colitis? Both Crohn's disease and Ulcerative colitis (including indeterminate colitis) 1.18. For the specified time period how many IBD patients did your service manage i.e. known to your service through inpatient admission, outpatient service or emergency department? a. Is this figure: an estimate or from a database/register? ☐Estimate ☐Database 1.19. How many IBD patients were seen in outpatients or associated clinics? Is this figure: an estimate or from a database/register? □Estimate □Database a. 1.20. How many new IBD patients has your centre seen for the specified period?

- a. Is this figure: an estimate or from a database/register?  $\ \square$  Estimate  $\ \square$  Database
- Up to what age are patients cared for in your service? 1.21.

## **Demographics**

Resr	onses for	r all remain	ing section	s should be	for a sna	pshot at 30	/11	/14

Responses for all remaining sections should be for a snapshot at 30/11/14		
2.1.	Does your hospital have a Gastroenterology Clinic?	☐ Yes ☐ No
2.2.	Does your hospital have a specific IBD Clinic?	☐ Yes ☐ No
2.3.	Do surgeons perform ileo-anal pouch surgery on site?	☐ Yes ☐ No
2.4.	Were the majority of these ileo-anal pouch operations carried conjunction with an adult colorectal surgeon?	out by a paediatric surgeon in
2.5.	How many FTE paediatric gastroenterologists are there on site?	
2.6.	How many general paediatricians with an interest in gastroente	rology are there on site?
2.7.	How many paediatric gastroenterologists fractional appointment appointment = 0.5 FTE or above.	nt/VMO/substantive
2.8.	How many FTE paediatric gastroenterologists in the unit have a on/responsibility for IBD?	clinical focus
2.9.	How many FTE paediatric colorectal surgeons are there on site?	
2.10.	How many FTE paediatric IBD nurse specialists (excluding clinical site?	al trial nurses) are there on
2.11.	How many FTE paediatric IBD nurse specialists have ongoing see	cure funded positions
2.12.	How many FTE paediatric clinical trial nurses are there on site?	
2.13.	How many FTE paediatric stoma nurses are there on site?	
2.14.	How many FTE paediatric dietitians or dietitians with suitable parallocated to gastroenterology?	aediatric experience are
2.15.	How many FTE administrators are attached to the IBD team?	
2.16.	What percentage of your patients with Crohn's disease were or	n infliximab?
2.17.	What percentage of your patients with ulcerative colitis were o	n infliximab?
2.18.	What percentage of your patients with IBD-unspecified were or	n infliximab?
2.19.	What percentage of your patients with Crohn's disease were or	n adalimumab?
2.20.	What percentage of your patients with ulcerative colitis were o	n adalimumab?

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2.21.	What percentage of your patients with IBD-unspecified were on adalimumab?
2.22.	What percentage of your patients with Crohn's disease were on immunomodulators such as azathioprine, mercaptopurine, thioguanine, methotrexate, mycophenolate, sirolimus, cyclosporine, tacrolimus
2.23.	What percentage of your patients with ulcerative colitis were on immunomodulators?
2.24.	What percentage of your patients with IBD-unspecified were on immunomodulators?
2.24.1.	Are the figures in 2.16 to 2.24 an estimate or from a database/register? EstimateDatabase
Clinic	al Quality
The IBI	D Team
3.1.	There is a defined access to a consultant paediatric gastroenterologist $\Box$ Yes $\Box$ No
3.2.	The IBD Service has a named clinical lead who is a paediatric gastroenterologist $\ \square$ Yes $\ \square$ No
3.3.	There is a clear pathway for referring IBD patients to a paediatric rheumatologist $\square$ Yes $\square$ No
3.4.	The IBD Service is supported by a radiologist with a special interest in paediatric gastroenterology $\Box$ Yes $\Box$ No
3.5.	The IBD Service is supported by a named pharmacist with a special interest in IBD or paediatric gastroenterology ☐ Yes ☐ No
3.6.	There is defined access to a named paediatric ophthalmologist $\ \square$ Yes $\ \square$ No
3.7.	The IBD Service is supported by a histopathologist with an interest in paediatric gastroenterology $\ \square$ Yes $\ \square$ No
Menta	l Health Services
3.8.	The IBD Service includes a paediatric mental health clinician $\square$ Yes $\square$ No
3.9. No	Paediatric patients with IBD can be referred to appropriate mental health services $\square$ Yes $\square$
3.10.	Families and carers of paediatric patients with IBD can be referred to appropriate mental health services $\;\Box$ Yes $\Box$ No
3.11.	Information is available for IBD patients who wish to access counselling support, e.g. via GP patient care plans   Yes  No
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Sexual	and Reproductive Health
3.12.	Age appropriate written information about IBD in pregnancy and its effects on fertility is available for patients $\Box$ Yes $\Box$ No
3.13.	Patients are given age-appropriate advice, when required, on issues regarding sexuality and body image. Teams can refer for specialist support locally as appropriate $\square$ Yes $\square$ No
3.14.	There is an agreed clinical pathway between adolescent gynaecology services and IBD Services for shared care $\Box$ Yes $\Box$ No
Multidi	sciplinary Working
3.15. Yes □ N	There is a multidisciplinary meeting in which complex IBD cases can be discussed lo
3.16.	How often do the multidisciplinary meetings occur? (evey x weeks)
3.17.	Decisions from the multidisciplinary team are documented in the patient notes and fed back to the patient $\ \ \Box$ Yes $\ \Box$ No
3.18.	There is an attendance at multidisciplinary team meetings by a paediatric gastroenterology dietitian AlwaysSometimesNever
3.19.	There is an attendance at multidisciplinary team meetings by a paediatric pharmacist
	AlwaysSometimesNever
3.20.	There is an attendance at multidisciplinary team meetings by an administrator
	AlwaysSometimesNever
3.21.	There are joint or parallel outpatient clinics for patients requiring joint medical and surgical care, which take place YesNo
3.22.	How often do the joint or parallel clinics occur? (Every X weeks)
Referra	of suspected IBD patients
3.23.	Suspected IBD patients can be referred to either paediatric gastroenterology, paediatric IBD or paediatric surgical clinics $\square$ Yes $\square$ No
3.24.	There is an agreed referral pathway for urgent paediatric out-patients between GPs and hospitals $\ \square$ Yes $\ \square$ No

3.25. All urgent referrals are seen within 4 weeks or more rapidly if clinically necessary

☐ Yes ☐ No

3.26.	Guidance has been developed to help GPs identify and refer symptomatic patients in whom IBD is suspected and when a review of diagnosis of patients with unresponsive, atypical or troublesome abdominal symptoms should occur
Access	s to nutritional support and therapy
3.27.	IBD patients can be referred to a paediatric dietitian experienced in the dietary management of IBD Yes, public service Yes, private service No
3.28.	Exclusive enteral nutrition as a primary treatment is available to patients with Crohn's disease, both as inpatients and outpatients $\Box$ Yes $\Box$ No
3.29.	Information given to all new IBD patients includes nutritional advice ☐ Yes ☐ No
3.30.	Regular assessment (minimum 4 monthly) occurs to ensure that nutritional intake is appropriate to facilitate normal growth and pubertal development $\Box$ Yes $\Box$ No
3.31.	Home enteral and, where applicable, home parenteral nutrition provision and monitoring is always available to patients either locally or by a regional centre $\ \square$ Yes $\ \square$ No
Arrang	gements for use of immunosuppressives and biologicals
3.32.	The hospital has a policy / protocol for screening for tuberculosis, hepatitis B and other relevant infections. $\Box$ Yes $\Box$ No
3.33.	A vaccination program for infections such as hepatitis B and Varicella zoster is considered before starting biological therapies. $\Box$ Yes $\Box$ No
3.34.	All patients and, when relevant, parents are counselled about the risk of malignancy and sepsis prior to starting immunosuppressive therapy. $\Box$ Yes $\Box$ No
3.35.	There are local protocols for the administration of biological therapies $\ \square$ Yes $\ \square$ No
3.36.	There is a process to ensure that patients on immunosuppressive treatment have their white blood count measured at least 3 monthly. $\Box$ Yes $\Box$ No
3.37.	Clinicians involved in the management of patients on immunosuppressives have access to a pharmacist with specialist knowledge/interest. $\Box$ Yes $\Box$ No
3.38.	Local protocols for the administration of biological therapies include pre-treatment, actions for infusion reactions and accelerated infusions $\Box$ Yes $\Box$ No
3.39.	A policy/protocol is available to guide the response of the IBD Service staff if white cell counts are low or other blood test abnormalities are observed; a named individual acts on abnormal results and communicates with GPs and patients, if appropriate

3.40.	Patients on immunosuppressive therapy have a choice as to whether their treatment is monitored by the hospital or in the community $\Box$ Yes $\Box$ No
3.41.	Patients receiving biological therapy are reviewed at least 3 monthly (either directly or by email/telephone) to monitor efficacy and adverse effects $\Box$ Yes $\Box$ No
3.42.	There is a local patient information sheet that includes advice on the action required if adverse events occur, that is given to all patients on immunosuppressive and biological treatments $\Box$ Yes $\Box$ No
3.43.	Clear shared-care arrangements for the monitoring and prescribing of immunosuppressive drugs are in place between primary and secondary care, including advice on the frequency of monitoring and what to do in the event of abnormal results $\Box$ Yes $\Box$ No
3.44.	IBD patients on both immunomodulator and biological therapy are subject to regular audit for outcome monitoring $\hfill \Box$ Yes $\hfill \Box$ No
Surgery	for IBD
3.45.	There is a formal regular governance process to review surgical morbidity and mortality within the hospital/health network, including review or audit of post-operative complications $\Box$ Yes $\Box$ No
3.46.	There are facilities and trained surgeons to offer laparoscopic /laparoscopically-assisted surgery where possible and if appropriate $\Box$ Yes $\Box$ No
3.47.	Complex surgical procedures are undertaken following joint discussion between medical/surgical and other multidisciplinary team members in a formal IBD Multidisciplinary Team Meeting or joint outpatient clinic.
3.48.	Patients being considered for pouch surgery are referred for expert pathological assessment where diagnostic uncertainty exists. $\Box$ Yes $\Box$ No
3.49.	Anaesthesia for IBD surgery is carried out by accredited paediatric anaesthetists $\square$ Yes $\square$ No
3.50.	One consultant surgeon with dedicated Paediatric IBD experience is the nominated lead for IBD surgery within the hospital/network. They support decision-making and/or surgery for complex IBD cases $\Box$ Yes $\Box$ No
3.51.	Pouch failure (and salvage) is managed in, or routinely referred to an agreed regional specialist unit, with appropriate expertise in re-operative pouch surgery YesNo ?
3.52.	There is annual review of IBD surgical service with review of activity, mortality and morbidity. $\Box$ Yes $\Box$ No

3.53.	There is an identifiable gastroenterology ward $\ \square$ Yes $\ \square$ No
3.54.	There is a paediatric intensive care unit (ICU) and a mixed medical/surgical high dependency unit (HDU). $\Box$ Yes $\Box$ No
3.55.	On the main ward that gastroenterology patients are managed, there is at least one toilet per 3 beds. $\Box$ Yes $\Box$ No
3.56.	Gastroenterology and colorectal surgical facilities are on the same site $\ \square$ Yes $\ \square$ No
3.57.	IBD or suspected IBD patients are usually triaged to the gastroenterology ward on admission $\Box$ Yes $\Box$ No
3.58.	The toilets have floor to ceiling partitions, full height doors and good ventilation $\square$ Yes $\square$ No
Access	to diagnostic services
3.59.	There is a gastrointestinal pathologist assessment available before surgery, which may involve referral of cases to a nationally recognised expert in the diagnosis and differential diagnosis, of chronic inflammatory bowel disease  YesNoUncertain
3.60.	For inpatients there is access to on-site ultrasound within 24 hours where required $\hfill\Box$ Yes $\hfill\Box$ No
3.61.	For inpatients there is access to on-site CT within 24 hours where required in a child friendly and suitably equipped environment $\Box$ Yes $\Box$ No
3.62.	For inpatients there is access to on-site MR within 24 hours where required a child friendly and suitably equipped environment $\Box$ Yes $\Box$ No
3.63.	It is routine practice for patients with acute severe ulcerative colitis to have a plain abdominal x-ray on admission $\Box$ Yes $\Box$ No
3.64.	X-ray reports of presence of toxic megacolon(transverse>4cm in children under10 years and >6cm in children over 10 years) are documented in the notes or on radiology report. Documentation is by the most senior member of the team who comments on initial X-ray $\square$ Yes $\square$ No
3.65.	Paediatric patients undergo endoscopy in an age-appropriate environment, carried out by someone with training or extensive experience in paediatric endoscopy and appropriate training recognized by the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy (CCRTGE) $\square$ Yes $\square$ No
3.66.	There is a process for urgent access to endoscopy, so that patients admitted with relapse can be scoped within 72 hours of admission $\Box$ Yes $\Box$ No
	All histological reports are available within 5 working days ☐ Yes ☐ No cric Organisational Audit — Extract 8.7.16 ped by Crohn's & Colitis Australia - IBD QoC Program

Inpatient facilities

3.68.	Urgent histology biopsies can be reported within 2 days $\square$ Yes $\square$ No		
3.69.	When required, drainage of an abscess can be carried out by interventional radiology $\hfill \Box$ Yes $\hfill \Box$ No		
3.70.	There is outpatient access to ultrasound/CT/MR studies and endoscopic assessment within weeks $\;\Box$ Yes $\Box$ No		
3.71.	Small bowel MRI is available as an alternative to CT scans ☐ Yes ☐ No		
3.72.	There is a consultant radiologist who primarily reports all paediatric gastrointestinal radiology in the hospital $\Box$ Yes $\Box$ No		
3.73.	Histology reporting times and outpatient waiting times for CT/MR and endoscopy are audited $\hfill\Box$ Yes $\hfill\Box$ No		
Inpatie	ent Monitoring		
3.74.	PUCAI (paediatric UC disease activity index score) is used at day 3 and 5 for assessment of patients with acute severe ulcerative colitis $\Box$ Yes $\Box$ No		
3.75.	The hospital has a policy / protocol that IBD patients have a weight and nutritional risk assessment, such as the STAMP, STRONGkids or PYMS score, on admission to hospital		
	□ Yes □ No		
3.76.	The hospital has a policy / protocol that IBD patients who have diarrhoea, have a stool sample sent for standard stool culture and Clostridium difficile toxin on admission		
	□ Yes □ No		
3.77.	The hospital has a policy / protocol that IBD patients have a stool chart recorded during hospitalisation $\;\Box$ Yes $\Box$ No		
3.78.	The hospital has a policy / protocol for suspected new IBD presentation $\ \square$ Yes $\ \square$ No		
3.79.	The hospital has a policy / protocol for flare of ulcerative colitis $\ \square$ Yes $\ \square$ No		
3.80.	The hospital has a policy / protocol for flare of Crohn's disease ☐ Yes ☐ No		
3.81.	The hospital has a policy / protocol for acute severe ulcerative colitis $\Box$ Yes $\Box$ No		
Inpatie	ent care		
3.82.	There is an acute pain management team available on site ☐ Yes ☐ No		
3.83.	Pain scores are routinely included in nursing observations for IBD patients ☐ Yes ☐ No		
3.84.	Inpatients have access to an IBD nurse during their admission $\qed$ Yes $\qed$ No		

3.85.	It is usual practice to refer an inpatient with severe pain (measured by pain scores) to the a cute pain management team $\Box$ Yes $\Box$ No
3.86.	There is access to a stoma nurse during hospitalization $\ \square$ Yes $\ \square$ No
3.87.	A named pharmacist with special interest in IBD is available to carry out inpatient drug reviews $\Box$ Yes $\Box$ No
Outpat	ient care
3.88.	All of the following are usually documented for all patients at clinic review: number of liquid stools per day, abdominal pain, weight loss, general well-being, psychological concerns, pubertal growth (Tanner staging) where required and height and weight recorded on appropriate percentile charts. $\Box$ Yes $\Box$ No
3.89.	Systems are in place to ensure that all patients currently under hospital review are identified and offered surveillance colonoscopy in accordance with guidelines. $\Box$ Yes $\Box$ No
3.90.	Steroid usage is recorded to ensure that patients who have had 3 months or continuous steroid use are identified $\Box$ Yes $\Box$ No
3.91.	All children with ulcerative colitis who have had the disease for more than 8 years are formally identified and a surveillance plan made and shared with adult services $\ \square$ Yes $\ \square$ No
3.92.	Bone densitometry is offered routinely to all patients who have received more than 3 months of corticosteroids. $\Box$ Yes $\Box$ No
3.93.	Annual data is collected and presented on: the percentage of patients who remain on steroids continuously for 3 months, the percentage of these patients discussed at MDT and the percentage started on additional therapy (e.g. immunosuppressives, anti-TNF or surgery). $\Box$ Yes $\Box$ No
Transit	ional care
3.94.	There is a transitional care service within the hospital to support young people being transferred from a paediatric service. A coordinator is responsible for the preparation and oversight of such transitional care(eg IBD nurse specialist) $\Box$ Yes $\Box$ No
3.95.	Each young person with IBD has an individual transition plan $\Box$ Yes $\Box$ No
3.96.	Age-appropriate written and verbal advice is provided on day-to-day management of symptoms and treatment $\ \square$ Yes $\ \square$ No
3.97.	Support and education is provided on lifestyle issues (e.g.sexual health, smoking, alcohol, recreational drug use) in young people with IBD $\square$ Yes $\square$ No
3.98.	The IBD service has a specific paediatric-to-adult transition policy $\square$ Yes $\square$ No
	Staff can refer young people to appropriate mental health services ☐ Yes ☐ No tric Organisational Audit — Extract 8.7.16 ped by Crohn's & Colitis Australia - IBD QoC Program

3.100.	There is a close working relationship with appropriate mental health services in clinics and on the ward $\ \ \Box$ Yes $\Box$ No
3.101.	The IBD service has a joint transition clinic with adult services $\Box$ Yes $\Box$ No
Patie	nt Experience
Inform	ation on the IBD Service
4.1.	Patients and carers are provided with written information regarding how to access IBD services and arrangements for follow up. $\Box$ Yes $\Box$ No
4.2.	All newly diagnosed patients and carers are given educational material routinely.
	□ Yes □ No
4.3.	All newly diagnosed patients and carers are offered a 'patient education' session routinely
	□ Yes □ No
4.4.	Your hospital routinely offers regular education opportunities for all IBD patients and their families, either as individuals or in groups. $\Box$ Yes $\Box$ No
4.5.	There is clear guidance as to how patients and carers can seek a second opinion if they wish. $\Box$ Yes $\Box$ No
Rapid a	access to specialist service
4.6.	There is written information for patients and carers with IBD on whom to contact in the event of a relapse $\Box$ Yes $\Box$ No
4.7.	Patients and carers have access to contact an IBD specialist nurse or doctor by telephone
	□ Yes □ No
4.8.	Patients and carers are able to contact an IBD specialist nurse or doctor via an email service $\Box$ Yes $\Box$ No
4.9.	Patients who contact the service via telephone or email are answered within 48 hours by an IBD specialist nurse or doctor $\Box$ Yes $\Box$ No
4.10.	Specialist review (face-to-face) for relapsed patients is available
	Within 7 working days
	8 to 14 working days
	Greater than 14 working days

Provision of information and supporting patients to exercise choice between treatments

4.11.	Written information about IBD and a range of treatments (e.g. CCA booklets) is available to all patients and carers $\Box$ Yes $\Box$ No
4.12.	Written information about IBD and the range of treatments (eg CCA booklets) is provided to patients and carers as part of the consultation to support the patient's decisions.
	□ Yes □ No
4.13.	There is access to a translator for all face-to-face and telephone contacts between patients and carers and the IBD specialist. Only answer 'yes' if a translator is available for ALL face-to-face and telephone contact. $\Box$ Yes $\Box$ No
4.14.	Information is available that is appropriate to the age, understanding and communication needs of patients $\ \square$ Yes $\ \square$ No
4.15.	A selection of written information is available for patients and carers in languages other than English $\Box$ Yes $\Box$ No
4.16.	Patients and carers are actively involved in management decisions about care, with a clear structured pathway for the patient to discuss his or her treatment with the gastroenterology, surgical, dietetics and other members of the multidisciplinary team
	□ Yes □ No
Suppor	ting patients to exercise choice between care strategies for outpatient management
4.17.	Stable patients who are referred back to primary care are given a clear plan about what to do in the event of a flare up $\Box$ Yes $\Box$ No
4.18	When a patient is discharged back to primary care, the GP is routinely given clear instruction about the need and criteria for annual review, including assessment of the need for: (select all that apply)
	Colorectal cancer surveillance
	Renal function
	Bone densitometry
	None
4.19	Patients are offered a choice of annual review including: (select all that apply)
	Hospital clinic
	Telephone clinic
	Review in primary care
	None

	telephone, video conference, shared data network/patient management system, personal electronic health record or hardcopy patient held file.
Involve	ement of patients in service improvement
4.21.	IBD patients are given the opportunity to provide feedback on their care
	□ Yes □ No
4.22.	At least one of the following means of assessing patient satisfaction is used:
	- An annual survey of a significant number of patients
	- IBD service subscribes to patient opinion or similar feedback service
	- Comment cards given to randomly sampled outpatients and inpatients
	□ Yes □ No
4.23.	Patients and carers are involved in service planning and improvement ☐ Yes ☐ No
4.24.	The service has an IBD patient panel or similar patient involvement group through which patients and carers discuss how the service might be improved with health professionals
	□ Yes □ No
4.25.	There has been reporting, followed by action planning and change implemented that was carried out as a result of the patient feedback of their care within the last year
	□ Yes □ No
Inform	ation and support for patient organisations
4.26.	Written information is made available to all new patients and carers, providing details of relevant patient organisations $\Box$ Yes $\Box$ No
4.27.	All IBD patients and carers are provided with information about their local patient support groups $\;\Box$ Yes $\Box$ No
4.28.	The IBD team circulate information about local support groups regularly e.g Crohn's and Colitis Australia, pouch and ostomy support groups. $\Box$ Yes $\Box$ No

If your service has a referral or communication relationship with another IBD service (either as provider or receiver of specialist advice) describe your communication process eg. email,

4.20.

# Research, Education and Audit

## Register of patients under the care of the IBD service

5.1.	The IBD service has a searchable database or registry of adult and paediatric IBD patients $\hfill \Box$ Yes $\hfill \Box$ No				
5.2.	The database is updated with clinical data about IBD patients receiving hospital care				
	□ Yes □ No				
5.3.	The database is updated with patients on biological therapy $\Box$ Yes $\Box$ No				
5.4.	The database is updated with patients on all immunosuppressives (including biological therapies) $\Box$ Yes $\Box$ No				
5.5.	The database is updated with clinical data about all patients with a diagnosis of IBD				
	□ Yes □ No				
Particip	pation in audit				
5.6.	All IBD inpatient deaths are reviewed by the IBD team, an action plan is formulated and action plan implementation is reviewed at least annually $\Box$ Yes $\Box$ No				
5.7.	There are mortality and morbidity meetings that are attended by a multidisciplinary team, to discuss any deaths and outcomes of surgery. These are minuted and have attendance registers. $\Box$ Yes $\Box$ No				
Trainin	g and education				
5.8. No	There are education opportunities focussed on IBD for all medical and nursing staff $\Box$ Yes $\Box$				
5.9.	The IBD team provides IBD training for GPs on an ad hoc basis ☐ Yes ☐ No				
Resear	ch				
5.10.	The IBD service provides access to age appropriate clinical trials $\ \square$ Yes $\ \square$ No				
5.11.	How many patients were entered into a clinical trial for UC/CD in the last year?				
5.12.	Do you collaborate on clinical trials with other sites? $\Box$ Yes $\Box$ No				
5.13.	All members of service are encouraged to participate in research, which is supported by the service with monetary support and/or flexible working arrangements $\Box$ Yes $\Box$ No				
5.13.1.	If 'yes' is this externally funded? $\Box$ Yes $\Box$ No				
Service	development				
	5.14. An annual review of the IBD Service is carried out				

5.15.	The annual review is attended by a multidisciplinary team of relevant professionals and			
	there is a reflection on the Service	☐ Yes ☐ No		
5.16.	An annual action plan is completed as a is reviewed as part of the organisation			