National Institute for Health and Care Excellence

Inflammatory bowel disease
Quality Standard Topic Engagement Comments Table

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	SCM 1	Availability of information in Plain English i.e. easy to read. The information should also be available as audio	The average reading age of the UK population is less than a 10 year old. It is important that people can understand their disease. About 10% of the population cannot read and so should be available as an audio or video presentation	It indicates that units are engaging with their population	Considerable published information on patients' requirement of information of their disease. Also identified in the relevant NICE Guidelines
002	SCM 1	Availability of information in the major local languages other than English e.g. Panjabi, Urdu, Gujarati, Polish, Welsh	A significant number of patients come from these minority groups. The information should be specifically developed for them and not simple translations of English versions	Again indicates engagement with the local population	Published research indicates that patients from minority groups experience discrimination and impaired access to care
003	SCM 1	Monitoring access to care for minority groups	There is evidence that patients from minority communities receive less good care and this is morally and legally unacceptable e.g. access to biologics is much lower in ethnic minority groups	It is an example of ensuring that patients have equal access to appropriate care	Again published studies
004	SCM 1	Choice of a female/male endoscopist	For some patients it is unacceptable to have the procedure done by someone of the opposite sex	It is an example of cultural sensitivity	Community groups and work on up-take in colorectal cancer screening programs
005	SCM 1	Creation of a register and responsible person for	Compliance with NICE Guideline	A basic standard of good care	NICE Guideline

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		monitoring azathioprine/mercaptopuriine /methotrextae toxicity as advocated in NICE guideline for Crohn's Disease			
006	SCM 2	All people with IBD should have access to an IBD specialist nurse service	IBD nurse specialists have become central to an IBD service and are valued very highly by people with IBD. They provide time to respond to questions, provide background information and support for patients at all stages of the disease. They are often involved with assessing and screening patients prior to immunosuppression and monitoring patients on treatment – all importantly addressed in NICE clinical guidance and TAs.	Access is not universal – ie there is significant variation in practice and Trusts put pressure on these posts because they may not generate as much income as other roles	Local audit in the Yorkshire and Humber region demonstrated a large proportion of people cared for in Trusts without IBD nurse specialist access.
007	SCM 2	All patients with acute severe ulcerative colitis should be appropriately assessed for the need for escalating treatment or surgery	Variation in practice, with variable assessment at key points during an admission	Inadequate assessment results in poor outcomes and inadequate use of rescue therapies.	See NICE CG166
008	SCM 2	All patients with	Failure to consider thiopurine	Corticosteroid side-effects are a	See NICE CG152 and CG166

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		IBD requiring two or more courses of corticosteroids in 12 months should be considered for thiopurine immunosuppression	immunosuppression in these situations may result in excess exposure to corticosteroids	significant cause of morbidity and impaired quality of life	
009	SCM 2	All patients with ulcerative colitis considering surgery should receive counselling that involves discussions with consultant gastroenterologists and colorectal surgeons, IBD nurse specialist and stoma therapists	Patients report feeling that more information prior to surgery would have been helpful	Definite variation in practice across the country.	See NICE CG166 Some debate as to what the counselling/pre-operative information should include
010	SCM 2	Ileoanal pouch surgery should be undertaken by accredited sub-specialists	Data can be debated but mean number of pouch operations is less than 1 per surgeon per year	Outcomes do seem to relate to numbers done and learning curve. Currently no driver to stop "occasional" surgeons doing this procedure.	Tekkis PP, Fazio VW, Lavery IC, Remzi FH, Senagore AJ, Wu JS, et al. Evaluation of the learning curve in ileal pouch-anal anastomosis surgery. Ann Surg 2005;241:262-8. Burns EM, Bottle A, Aylin P, Clark SK, Tekkis P, Darzi A, et al. Volume analysis of outcome following restorative proctocolectomy. Br J Surg 2011;98:408-17.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					RavalMJ, SchnitzlerM, O'Connor BI, Cohen Z,McLeod R. Improved outcome due to increased experience and individualized management of leaks after ileal pouch-anal anastomosis. Ann Surg 2007;246:763-70.
011	SCM 3	Attendance at school > 90 %	Attendance at school > 90 %	There are clear indicators that define children attending school less than 90% of the time as losing in multiple ways in the long term (including education achievement, requirement for benefits etc). Maximising school attendance and educational achievement has multiple long term benefits both for the individual and the State. In general it also indicates reasonable overall quality of health in the short term.	School data and outcomes ?
012	SCM 3	Satisfactory transition of all children with IBD	Poor transition processes are shown to lead to poor compliance and thus poor health etc. Often at a crucial time for the individual who may be going to further for higher education or starting work.	Maximise health at a most vulnerable, uncertain and difficult time	Transition papers etc
013	SCM 3	Diagnosis of Paed IBD	Diagnosis and initiation of treatment of Crohn’s diseases confirmed within a maximum of 6 months of onset of symptoms. UC less than 8 weeks.	Delayed diagnosis is one of the most common complaints of all patients and families and can take a year or more. Requires joined up processes from primary care to the tertiary unit where the diagnosis is confirmed.	CICRA survey ?
014	SCM 3	Final adult height in children	Failure to achieve growth potential is an indicator of the	High quality paediatric care, with expert knowledge of growth and	Sawczenko etc. Measurement of puberty and growth.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		diagnosed with UC or Crohn's	quality of the care. This is usually more a measure of the medical care provided in the tertiary unit than the primary care processes.	puberty and how to manage this is not done well outside tertiary units. Keeping control of disease with minimal use of steroids and decision making about growth issues at the right time is essential for this.	
015	SCM 3	Avoidance of unplanned admission for IBD	Avoidance of emergency admission for IBD. As a chronic disease one of the markers of a high quality service is the avoidance of unplanned admissions for IBD.	A high number of unplanned admissions some cases imply a failure of the overall coordination of care from primary care to tertiary care. This is either poor care so more children become acutely unwell, or is poor provision of services and beds for what should be planned admissions and so children are brought in unnecessarily via the emergency route.	See Map 24 NHS Atlas of Variation in Healthcare for Children and Young People (March 2012) http://www.hsj.co.uk/resource-centre/best-practice/care-pathway-resources/mapping-variation-to-prioritise-areas-needing-improved-outcome-quality-and-productivity/5043511.article#.UtAkhPvFqSo
016	Royal College of Paediatrics and Child Health	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the inflammatory bowel disease topic engagement exercise. We have not received any responses for this consultation			
017	Royal College of Pathologists	Inflammatory bowel disease (IBD) biopsy pathology: accuracy, consistency, and speed of reporting	Accurate and timely reporting of biopsies taken for IBD diagnosis is important for confirmation of the diagnosis of IBD, its subclassification as Crohn's disease or ulcerative colitis (UC), detection of dysplasia, and exclusion of co-existent conditions. Also, histological activity is a predictor of the risk of dysplasia.	There appear to be inconsistencies within the UK, some of which were highlighted by a national audit. There were variations in the approach to reporting, the use of terminology, and available resources. Also, suggested turnaround time targets (e.g. Royal College of Pathologists; UK IBD Standards group) are probably not being met consistently.	UK (BSG) IBD biopsy pathology guidelines: http://www.ncbi.nlm.nih.gov/pubmed/23999270 UK (BSG) audit of IBD pathology: http://www.ncbi.nlm.nih.gov/pubmed/17630400 European (ECCO) guidelines, Crohn's disease: http://www.ncbi.nlm.nih.gov/pubmed/164

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					81628 European (ECCO) guidelines for UC: http://www.ncbi.nlm.nih.gov/pubmed/21172194 Turnaround times (RCPath): http://www.rcpath.org/Resources/RCPath/Migrated%20Resources/Documents/K/KPI%20review%20v3%202011%20final%20TH%20%20web%20v(2).pdf. Turnaround times (IBD Standards): http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf.
018	Royal College of Pathologists	Reporting of IBD resection pathology	Accurate reporting of IBD resections is important. The reasons are similar to those given above for biopsies. It is particularly important to assess a subtotal colectomy accurately because ileal pouch-anal anastomosis is typically offered to those with UC but not to those with Crohn's disease.	Similar to biopsy reporting. Inconsistencies have been suggested by audits.	UK (BSG) audit of IBD pathology summary: http://www.ncbi.nlm.nih.gov/pubmed/17630400 UK IBD Standards document: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf.
019	Royal College of Pathologists	Better definition of referral pathways for difficult IBD pathology cases	The assessment of cases which are difficult to classify may be improved by the input of a recognised expert histopathologist. This has been noted by a UK IBD Standards document.	Suggested referral pathways for non-tumour pathology may be poorly defined or non-existent. Definition of suggested pathways should be helpful.	UK IBD Standards document: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf.
020	Royal College of Pathologists	Clinicopathological correlation when	The accuracy of interpretation of IBD biopsies and resections	Audit has shown that the quality of clinical information supplied to	UK (BSG) audit of IBD pathology summary:

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		reporting IBD biopsies and resections	is improved if there is correlation of pathology with clinical and endoscopic findings. This includes discussion at a relevant clinicopathological meeting.	histopathologists is variable. For example, fewer than 50% of respondents judged the clinical information supplied as "usually" or "always" adequate; endoscopy reports were usually not provided; and clinicopathological meetings were not consistently available. The need for improved interaction between clinicians and pathologists has been highlighted in European and US guidelines and by the UK IBD Standards Group. The value of providing the endoscopy report is emphasised in recent UK guidelines for gastroenterologists.	http://www.ncbi.nlm.nih.gov/pubmed/17630400 UK (BSG) IBD biopsy pathology guidelines: http://www.ncbi.nlm.nih.gov/pubmed/23999270 European (ECCO) IBD guidelines: http://www.ncbi.nlm.nih.gov/pubmed/16481628 US recommendations http://www.ncbi.nlm.nih.gov/pubmed/12094842 UK IBD Standards http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf. UK (BSG) guidelines for gastroenterologists http://fg.bmj.com/cgi/content/full/flgastro-2013-100413
021	Royal College of Pathologists	Adequacy of biopsy sampling of IBD mucosa	Histological assessment of multiple site colonoscopic biopsies rather than single site biopsies yields significantly greater diagnostic accuracy and better interobserver agreement. Suboptimal sampling is a recognised reason for inaccurate diagnosis of IBD, particularly in relation to Crohn's disease. Clinical and pathological	Sampling within and between sites should be adequate. In turn, the site of origin of each biopsy should be clear, especially if histological distinction between UC and Crohn's disease is expected. Audit showed that the anatomical site of origin of IBD biopsies was unclear to the reporting pathologist in a significant minority of cases.	UK (BSG) audit of IBD pathology: http://www.ncbi.nlm.nih.gov/pubmed/17630400 UK (BSG) guidelines for gastroenterologists: http://fg.bmj.com/cgi/content/full/flgastro-2013-100413 Recommendation for multiple site biopsies in European guidelines http://www.ncbi.nlm.nih.gov/pubmed/164

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			guidelines consistently emphasise these points.		81628
022	Dr Falk Pharma UK Ltd	**Therapy choice and optimisation**	There is evidence that appropriate therapy aids adherence, reducing relapses and the associated issues and costs. There is evidence of inappropriate therapies being used for ulcerative colitis (UC) and Crohn's disease (CD). For example, starting UC therapy with biologics when a 5-aminosalicylate such as mesalazine would be better and using systemic corticosteroids or mesalazine for CD when budesonide would be better. In maintenance, three times daily dosing can lead to lack of adherence whereas a once daily regime would aid adherence. Dose escalation/optimisation is needed before therapy is changed. Use of most appropriate formulation and of rectal/oral combination.	Not optimising therapy can result in relapses and an associated possible increase in risk of colorectal cancer, unnecessary escalation of therapy, increased costs, reduced quality of life and avoidable side effects. Effort is needed in all areas of optimisation. Patients need better access to an IBD healthcare professional (HCP) particularly if flare/relapse occurs to obtain the most appropriate therapy/support to regain maintenance.	*Taylor, K. M. & Irving, P. M. Optimization of conventional therapy in patients with IBD.* Nat. Rev. Gastroenterol. Hepatol. *2011; 8, 646–656* Which oral aminosalicylate for ulcerative colitis? Drug and Therapeutics Bulletin. *British Medical Journal*. 49;1. January 2011 Kane S. Systematic review: adherence issues in the treatment of ulcerative colitis. *Aliment Pharmacol Ther* 2006; 23:577–585 Loftus E.V. A Practical Perspective on Ulcerative Colitis: Patients' Needs from Aminosalicylate Therapies. *Inflamm Bowel Dis* 2006;12:1107–1113 Dignass A, van Assche G, Lindsay JO. *et al.* The second European evidence-based Consensus on the diagnosis and management of Crohn's disease: Current management. J Crohn Colitis. 2010;4(1):28-62. Travis S.P.L. Stange E.F. Lémann, M.Øresland T, Bemelman W.A., *et al* European evidence-based Consensus on the management of ulcerative colitis: Current management. For the European Crohn's and Colitis Organisation (ECCO) *Journal of Crohn's*

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					and Colitis (2008) 2, 24–62
023	Dr Falk Pharma UK Ltd	**Education**	Patients do not always understand the importance of following the prescribed treatment, resulting in relapses leading to unnecessary escalation of treatment (e.g., to (expensive) biologics potentially leading to avoidable side effects), hospitalisation, reduced quality of life. HCP need to understand that relapse due to non-compliance does not necessarily need escalation of treatment.	Some reports place non-adherence from 43% - 72% other reports have it as low as 30%. Non-adherence leads to relapses and an associated possible increase in risk of colorectal cancer, unnecessary escalation of therapy, increased costs, reduced quality of life and avoidable side effects.	Kane SV, Cohen RD, Aikens JE, Hanauer SB. Prevalence of non-adherence with maintenance mesalamine in quiescent ulcerative colitis. *Am J Gastroenterol* 2001; 96: 2929–33. Hawthorne A. B., Rubin G., Ghosh S Review article: medication non-adherence in ulcerative colitis – strategies to improve adherence with mesalazine and other maintenance therapies *Aliment Pharmacol Ther* 27, 1157–1166 Higgins P. D. R. , Rubin D. T., Kaulback K., Schoenfield P. S. , Kane S. V. Systematic review: impact of non-adherence to 5-aminosalicylic acid products on the frequency and cost of ulcerative colitis flares *Aliment Pharmacol Ther* 2009; 29:247–257
024	Dr Falk Pharma UK Ltd	**Stable therapy**	It has been shown that treatment switches in adherent mesalazine patients lead to greater risk of relapse.	Caution is needed when considering switching stable, adherent, patients on mesalazine. The risk of relapse due to switch can result in greater costs not savings. Costs include financial cost of product, hospital admittance, patient quality of life etc.	Robinson A, Hankins M, Wiseman G, Jones M. Maintaining stable symptom control in inflammatory bowel disease: a retrospective analysis of adherence, medication switches and the risk of relapse. *AP&T.* 2013; doi:10.1111/apt.12396
025	Association for Clinical Biochemistry and	Medical management of IBD	There is evidence that appropriate medical management leads to faster remission and is cost effective	There is variation in management regimens and in availability of potential therapies	BSG guidance 2010 RCP National audit of biological therapies 2013 NICE clinical guidelines 166,152

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Laboratory Medicine				technical appraisals 163, 140
026	Association for Clinical Biochemistry and Laboratory Medicine	Laboratory monitoring to support patients with IBD	There is evidence that laboratory testing assist diagnosis and therapeutic decision making and can result in cost savings	There is variation in existing laboratory practice with respect to diagnostic and monitoring test and in screening performed prior to initiation of therapy. In addition new commercial products have been developed since the development of existing guidance which may impact on this area	BSG guidelines 2010 NICE diagnostics guidance 11 RCP National audit of biological therapies 2013
027	Association for Clinical Biochemistry and Laboratory Medicine	Appropriate multidisciplinary care for patients	Effective team working is an important factor for clinical care. Routine involvement of IBD nurses in day to day care is likely to be a driver for service improvement	There is known to be patient dissatisfaction with respect to consistency and co-ordination of care and nursing care.	RCP UK IBD Audit (3rd Round)
028	Association for Clinical Biochemistry and Laboratory Medicine	Preventable complications	IBD is a long term condition and management should involve monitoring for complications	It is known that there is variation in clinical practice	NICE CG118, CG146
029	Association for Clinical Biochemistry and Laboratory Medicine	Arrangements for care of paediatric patients and transition to adult services	Children require separate models of care and specific arrangements for transition	There is regional variation in ease of access to specialist paediatric gastroenterology services	BSPGHN Guidelines for the Management of IBD in Children 2008 National Service Framework for Children, Young People and Maternity Services 2004
030	Queen Elizabeth Hospital Birmingham	**Management of anaemia in IBD**	Up to 40% patients with IBD have prevalent anaemia which is the most common extra-intestinal complication of IBD	This is an area which neglected by clinicians and in which there have been recent developments in therapies involving safe new IV iron preparations. There is little in existing national	I chaired the recent ECCO subcommittee on the treatment of iron deficiency anaemia in IBD. This committee will shortly publish an update to the 2007 ECCO guidelines on anaemia management in IBD

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				IBD guidelines about anaemia management	
031	NHS Direct	NHS Direct confirmed that they had no comments to make.			
032	NHS England	High Quality Clinical Care	A service encompassing local and specialist care, physicians and surgeons, the full MDT of other healthcare professionals (particularly dietitians, pharmacists and psychologists), the latest evidenced based treatments, a patient-centered approach, and good paediatric to adult transition is the current gold standard	IBD services are currently of variable quality around England	IBS Standards 2013 UK IBD Audit 3rd round
033	NHS England	Improved Data, IT and Audit	National Audits have clearly shown a variable IBD service and that audit leads to improved care. There are now available excellent standard, audits and IT systems to set up a cycle of excellent care and continuous improvement	These area will be the key drivers to improvement	IBD Standards 2013 UK IBD Audit 3rd round http://ibdregistry.org.uk
034	NHS England	Evidenced-based Practice and Research	The evidence base for IBD treatments is both long and deep.	The evidence suggests that there should be increased use of stronger treatments, but these clearly need to be used appropriately and not over used.	Mowat C et al. On behalf of the IBD Section of the British Society of Gastroenterology Guidelines for the management of inflammatory bowel disease in adults. Gut (2011). doi:10.1136/gut.2010.224154
035	NHS England	Patient Education and Support	The majority of patients are in a younger age group, and will be more than keen to take control of the management of their own illness	Having patients in control of their own illness will improve outcomes, reduce risk and side effect, and reduce the burden on health services	IBD Standards 2013
036	SCM 4	Key area for	Undernutrition is common in	**Not all in-patients with IBD are**	Geerling BJ, Badart-Smook A,

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		quality improvement 1 **All in-patients and out-patients with IBD should undergo regular nutritional screening**	IBD (both CD and UC) during both relapse and remission, resulting in reduced muscle strength, fatigue, specific nutrient deficiencies and impaired psycho-social function. The NICE guidelines for nutritional support in adults (CG32) recommend that all in-patients should undergo nutritional screening on admission and weekly thereafter. It also recommends screening in out-patients at risk of protein-energy undernutrition (NICE, 2006).	**weighed, let alone undergo a full nutritional screening**. The IBD audit (round 3) indicated that 74.7% of in-patients with CD were weighed. However this ranged from 0% to 100% between different Trusts in the UK (RCP, 2012). Data is not available on subsequent weekly weight monitoring, and no data is available on the prevalence of weighing in UC, nor in any out-patients with IBD, despite undernutrition occurring in these groups.	Stockbrugger RW, Brummer RJ. Comprehensive nutritional status in patients with long-standing Crohn's Disease currently in remission. Am J Clin Nutr 1998; 67: 919-26. NICE (2006) Guidelines for Nutrition support in adults (CG32) http://www.nice.org.uk/cg32 RCP (2012). Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in the UK. Round 3. February 2012 http://www.rcplondon.ac.uk/projects/ibdauditround3
037	SCM 4	Key area for quality improvement 2 **All IBD services should have dedicated access to an IBD-specialist dietitian**	Undernutrition is common in IBD (both CD and UC) during both relapse and remission. Where screening indicates that patients with IBD have (or are at risk of developing) undernutrition specialist dietary advice from a dietitian is required (NICE, 2006). A specialist dietitian can provide dietary counselling to improve nutrient intake from food or oral nutritional supplements, both of which have been shown to improve nutritional and clinical outcome (Imes et al, 1988; Baldwin	**A minority of in-patients are seen by a dietitian**. The IBD audit (round 3) indicated that only 39.7% of in-patients with CD were seen by a dietitian. However this ranged from 0% to 100% between different Trusts in the UK. This is despite their recommendation that "a dietician should see all Crohn's disease inpatients" (RCP, 2012). **Few IBD services have the recommended number of dietitians dedicated to IBD**. In our national survey of all NHS Trusts in the UK (Lomer et al, 2014), a median of 0.2 WTE were dedicated to gastroenterology. Thirty-three	Baldwin C,Weekes CE. Dietary advice with or without oral nutritional supplements for disease related malnutrition in adults. Cochrane Database Syst Rev. 2011 Sept 7;9: CD002008. IBD Standards Group (2013). Standards for the Healthcare of People who have Inflammatory Bowel Disease. http://www.ibdstandards.org.uk/ Imes S, Pinchbeck B, Thomson A.B.R. Dietary Counselling improves the clinical course of patients with Crohn's Disease. Digestion 1988; 39: 7-19 Lomer MC, Gourgey R, Whelan K.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			2011; NICE 2006). Dietitians are essential in the nutritional management of other aspects of IBD. For example, enteral nutrition can be used to induce remission of CD. In addition, dietitians can provide dietary advice and monitor functional symptoms in IBD and iron and calcium status. The IBD Standards recommend that for a defined local population of 250,000, an IBD Team should have a minimum of 0.5 WTE dietitians (Standard A1) and that access to a dietitian should be available to all IBD patients (Standard A5). In our national survey of all NHS Trusts in the UK (Lomer et al, 2014), we demonstrated that patients with CD had improved nutritional assessment if they were seen in IBD services with ≥0.5 WTE dietitians, than in those with <0.5 WTE dietitians.	(25%) of departments did not have any dietetic sessions dedicated to gastroenterology. Only 31 (23%) departments achieved IBD Standards recommendation of ≥0.5 WTE dietitians dedicated to gastroenterology.	Current practice in relation to nutritional assessment and dietary management of enteral nutrition in adults with Crohn's disease. J Hum Nutr Diet. 2014. [Epub ahead of print] NICE (2006) Guidelines for Nutrition support in adults (CG32) http://www.nice.org.uk/cg32 RCP (2012). Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in the UK. Round 3. February 2012 http://www.rcplondon.ac.uk/projects/ibdauditround3
038	SCM 4	Key area for quality improvement 3 **Patients with**	Osteoporosis is common in IBD, occurring in up to 57% of patients, resulting in a considerably elevated fracture	**There is suboptimal monitoring for calcium intakes and prescription of calcium supplements**. In the IBD audit (2nd	BSG (2007). Guidelines for osteoporosis in inflammatory bowel disease and coeliac disease.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		IBD should have calcium status assessed and appropriate intervention provided where required	risk (RR up to 1.7)(BSG, 2007). The recommended calcium intake in IBD is 1000 mg/d, including supplementation where required (BSG, 2007).	round), calcium supplementation rates in those discharged on steroids was only 51%.	RCP (2008). Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in the UK. Round 2. 2008 http://www.rcplondon.ac.uk/projects/ibdauditround2
039	SCM 4	Key area for quality improvement 4 **Patients with IBD should have iron status assessed and appropriate intervention provided where required**	Iron deficiency is common in patients with IBD (up to 40% in adults) and results in a significant negative impact on QoL (Goodhand et al, 2012). The BSG guidelines and ECCO consensus statement highlight the importance of screening for Fe deficiency and treating with oral or intravenous replacement therapy were appropriate (Mowatt et al, 2012).	**There is suboptimal treatment for Fe deficiency.** Only a minority of iron deficient patients with IBD are given oral iron supplements (13% children, 30% adolescents, 48% adults) or intravenous iron (0% children, 30% adolescents, 41% adults) (Goodhand et al, 2012).	Avni T, Bieber A, Steinmetz T, Leibovici L, Gafter-Gvili A.Treatment of anemia in inflammatory bowel disease- systematic review and meta-analysis.PLoS One. 2013 Dec 2;8(12):e75540. doi: 10.1371/journal.pone.0075540 Goodhand JR, Kamperidis N, Rao Laskaratos AF, McDermott A, Wahed M, Naik S, Croft NM, Lindsay JO, Sanderson IR, Rampton DS. Prevalence and management of anaemia in children, adolescents and adults with inflammatory bowel disease. Inflamm Bowel Dis, 2012 Mar;18(3):513-9. Mowat C, Cole A, Windsor A, Ahmad T, Arnott I, Driscoll R, Mitton S, Orchard T, Rutter M, Younge L, Lees C, Ho GT, Satsangi J, Bloom S; IBD Section of the British Society of Gastroenterology. Guidelines for the management of inflammatory bowel disease in adults. Gut. 2011 May;60(5):571-607.
040	SCM 5	Key area for	IBD surgery should be	High quality surgery for Crohn's	1. IBD Standards (2013)

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		quality improvement 1	undertaken by colorectal surgeons working within a unit where IBD operations are performed regularly and by surgeons who are core members of the IBD team. Within this framework patients should have access to a joint medical-surgical IBD clinic.	and Ulcerative Colitis demands that it is undertaken by experienced IBD specialists. Evidence suggests that outcome following complex surgical procedures, such as pouch surgery, is better when carried out in high surgical volume institutions.	http://www.ibdstandards.org.uk/ 2. Burns EM, Bottle AB, Aylin PA et al, Br J Surg 2011 Mar98(3):408-17
041	SCM 5	Key area for quality improvement 2	Patients who are failing medical therapy should be managed jointly in IBD units with appropriate specialist gastroenterology and surgical skills. The latter should include facilities for laparoscopic surgery.	Collaborative working between surgeons and gastroenterologists is important to achieve good outcome in IBD surgery.	1. IBD Standards (2013) http://www.ibdstandards.org.uk/ 2. IBD Audit Third Round http://www.rcplondon.ac.uk/sites/default/files/national-adult-uk-ibd-inpatient-care-audit-report-round-3_0_0.pdf
042	SCM 5	Key area for quality improvement 3	Access to Specialist Surgical Care – patients requiring pouch excision or pouch salvage should be performed in high volume IBD centres with appropriate specialist pouch surgical skills. Similarly, patients requiring intestinal failure services (due to short bowel or enterocutaneous fistula) should be cared for in specialist centres.	Highly complex rare procedures should be undertaken in specialist centres with appropriate personnel and facilities to manage such patients.	NHS England - Clinical commissioning for Colorectal: complex Inflammatory Bowel Disease (adult) http://www.england.nhs.uk/wp-content/uploads/2013/06/a08-colore-inflam-bowel-disease-adult.pdf
043	SCM 5	Key area for quality improvement 4	Simple metrics on caseload as well as immediate and delayed complications after surgery should be formally audited. Where national databases	Data collection is a fundamental aspect of performance measurement and quality improvement in surgery.	1. IBD Standards (2013) http://www.ibdstandards.org.uk/ 2. ACPGBI UK Ileal Pouch Registry (2012) (http://demo.e-

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			exist, such as the ACPGBI Ileal Pouch Registry, cases should be submitted.		dendrite.com/csp/ilealpouch/frontpages/ipdbfront.csp)
044	SCM 5	Key area for quality improvement 5	Regular IBD multidisciplinary meetings should take place with a facility for minuting management outcome.	Multidisciplinary team working underpins high quality service delivery.	1. IBD Standards (2013) http://www.ibdstandards.org.uk/
045	SCM 6	Key area for quality improvement 1: **Patient-Centred, Age-Appropriate Care**	Patient-centred care is recommended within NICE guidance and the NHS Constitution. It should be age appropriate and be responsive to individual needs. It should include the patient in all decisions with regard their care. IBD is a relapsing and remitting condition with substantial differences in the way it affects individuals. There can also be significant differences in the complexity and symptoms within any one patient. Patients in remission are often expected to self-manage their condition and to be aware of when it is deteriorating and the route back into care. The nature of IBD is that this is sometimes an urgent requirement.	The IBD Audit indicates that: 13% of IBD inpatients felt that they were not involved in decisions about discharge. 11% reported no written information about discharge medicines. 30% reported that no staff member had told them about danger signals to be aware of after going home. 17% stated that they were not given enough information about how to manage their condition. 40% state that they did not receive a copy of letters exchanged between their hospital and their GP. The IBD Audit also identified a lack of age-appropriate facilities for children and young people being treated within adult IBD services. Less than half of the services which look after patients aged 16 or under stated that they had a specific paediatric to adult transition policy.	IBD Standards Update 2013 - www.ibdstandards.org.uk UK IBD Audit Round 3 reports - www.rcplondon.ac.uk/projects/ibdauditround3/ NICE Quality Standard: Patient experience in adult NHS services. NHS Constitution: The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services. RCN Inflammatory Bowel Disease Nursing Audit - www.rcn.org.uk/__data/assets/pdf_file/0

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				71% of paediatric services do not have arrangements for annual outpatient review. 65% provide education for patients and their carers.	008/433736/004197.pdf British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009 - www.bspghan.org.uk/documents/IBDGuidelines.pdf
046	SCM 6	Key area for quality improvement 2: **Patient Education and Support**	IBD care must allow patients to understand their condition and the management of that condition. IBD patients must be in a position to make informed decisions with their medical team when considering their treatment options and in managing their condition outside primary and secondary care thus allowing them to maintain the best quality of life possible while being fully aware of the danger signs of deterioration.	The IBD Audit indicates that a significant number of patients report inadequate information on drug side effects and danger signs or how to manage their condition after discharge. Only one third of services provide a written care plan and patient education is only available in 57% of services. The IBD Audit has also found that access to psychological, dietetic and specialist nursing support is at inadequate levels. This is detrimental to allowing patients to understand and effectively manage their condition. Evaluation of information from the patient's perspective is required to ensure that their requirements are met. There is a wide range of information available particularly via the internet. This can be helpful if	IBD Standards Update 2013 - www.ibdstandards.org.uk UK IBD Audit - www.rcplondon.ac.uk/projects/ibdauditround3/ Coulter A, Ellins J, Effectiveness of strategies for informing, education and involving patients, British Medical Journal, 2007; 225:24. Adams, RJ, Improving health outcomes with better patient understanding and education, Journal of Risk Management and Healthcare Policy, 2010; 3; 61-72

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				the information is high. However, there is much low quality, unregulated information available providing poor and misleading information. Patient education must help the patient understand quality information and signpost them accordingly.	
047	SCM 6	Key area for quality improvement 3: **Rapid Access to High Quality Clinical Care**	High quality, safe and integrated clinical care for IBD patients based on multidisciplinary teams is essential for the safe and effective management of IBD. Rapid referral of people with suspected IBD is important to avoid delay in diagnosis and trigger early treatment. Given the psychosocial impact of IBD, psychological and quality of life assessment is also essential.	Symptoms of IBD often include urgent and frequent diarrhoea, rectal bleeding, pain, fatigue, general malaise and anaemia. There are sometimes extra intestinal symptoms including joints inflammation, skin problems, and inflammation of the liver or eyes. Malnutrition and sometimes dramatic weight loss are common, particularly in Crohn's disease. Severe cases of IBD may lead to life-threatening. Delayed diagnosis can have dramatic effects including serious and rapid onset of complications and a substantial impact on the patient's quality of life. The IBD audit indicates that only 24% of GPs felt "very confident" in recognising the key symptoms of IBD and only 6% are "very confident"" in dealing with acute exacerbations of IBD. Most GPs expressed a desire for	BSG guidelines: Malnutrition in IBD is common and multi-factorial in origin. IBD Standards Update 2013 - www.ibdstandards.org.uk UK IBD Audit - www.rcplondon.ac.uk/projects/ibdauditround3/

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				educational support and management in IBD. Over 40% of GPs found lines of communication with secondary care to be slow and over 10% did not always know who to contact. The IBD Audit has also found that 60% of non-elective adult patients with Crohn's Disease were not seen by a Dietitian and only 24% of adult services have defined access to a psychologist with an interest in IBD.	
048	SCM 6	Key area for quality improvement 4: **Local Delivery of Care**	Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.	Currently the majority of IBD care is provided in secondary care. Some aspects of the management of adults with IBD could be provided in primary care and this would take services closer to the patient. Some Specialist IBD Nurses outreach into primary care to help bring expert care closer to the patient and this is beneficial and could be further developed.	IBD Standards Update 2013 - www.ibdstandards.org.uk
049	SCM 6	Key area for quality improvement 5: **Evidence-Based Practice and Research**	A service that is knowledge-based and actively supports service improvement and clinical research.	High level training in Inflammatory Bowel Disease to all healthcare professionals involved in IBD care in both primary and secondary care to enable them to provide skilled, specialist and patient-centred care to high standards. The principle of a knowledge-based service requires that necessary research should be identified and	IBD Standards Update 2013 - www.ibdstandards.org.uk

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				prioritised.	
050	UK Clinical Pharmacy Association	Key area for quality improvement 1 **Patient-centred and age-appropriate care**	no additional comments	*No additional information provided by stakeholder*	*No additional information provided by stakeholder*
051	UK Clinical Pharmacy Association	Key area for quality improvement 2 **High quality patient information and support to enable informed decision making and effective self-management**	Pharmacists are an easy point of access for patients and ideally placed to support patients when managing their medication supply.	Pharmacists can contribute considerably to support information and education and facilitate decision making and self management. Awareness of this resource is inadequate and skills are underused.	IBD Standards, Standard D: Patient Education and Supporthttp://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=20
052	UK Clinical Pharmacy Association	Key area for quality improvement 3 **Pathways for rapid referral and specialist assessment where IBD is suspected**	no additional comments	*No additional information provided by stakeholder*	*No additional information provided by stakeholder*
053	UK Clinical Pharmacy Association	Key area for quality improvement 4 **Care and treatment to induce and maintain steroid-free remission**	Pharmacists are important team member to ensure timely introduction and access to expensive and novel treatments and the management of medication risks.	Access to suitably trained specialist pharmacists is currently not guaranteed and fairly patchy.	IBD Standards, Standard D: Patient Education and Supporthttp://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=20

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
054	UK Clinical Pharmacy Association	Key area for quality improvement 5 **Access to appropriate specialists when needed and, specifically, within 5working days in the event of a potential relapse**	no additional comments	*No additional information provided by stakeholder*	*No additional information provided by stakeholder*
055	Vifor Pharma UK Ltd	**Management of iron deficiency (ID) and iron deficiency anaemia (IDA) in patients with inflammatory bowel disease (IBD)**	ID occurs in 60-80% of patients with IBD, and anaemia manifests in approximately one-third of patients. Anaemia is thus by far the most common extra-intestinal complication of IBD.	Management of IDA in IBD is sub-optimal, with a significant impact on patients' quality of life. There is scant clinical guidance on the management of IDA in existing national IBD guidelines, making this complication undertreated in the context of the primary condition. Whilst there have been some improvements in the standards for healthcare of people with IBD in recent years, anaemia is not, to date, included in any standard. Unplanned hospital admissions due to IDA are a burden on the healthcare system despite there being recognised treatments to effectively treat IDA.	The supporting information is highlighted to demonstrate the lack of guidance on the management of IDA in IBD. Ulcerative colitis. NICE clinical guideline 166 (2013) Crohn's disease. NICE clinical guideline 152 (2012) Guidelines for the management of inflammatory bowel disease in adults. British Society of Gastroenterology (2010) Standards for the healthcare people who have inflammatory bowel disease (IBD). IBD Standards 2013 Update. Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in the UK. Round 3. Royal College of Physicians (2012).
056	Royal College of Physicians.	Key area for quality improvement 1 **Patient-centred and age-**	Patient-centred and age-appropriate care is recommended within NICE guidance and the NHS Constitution. It is a vital part of	UK IBD audit data have demonstrated: - Nurse provision falls below recommended levels - 32% of patients are being	The rationale for many key areas of improvement included in this response can be found in the UK IBD audit round 3 reports: www.rcplondon.ac.uk/ibd - Inpatient experience report

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		appropriate care	all clinical interactions, including diagnostics investigations, inpatient and outpatient care. IBD follows an unpredictable relapsing and remitting course, with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her life. Therefore, patient-centred care needs to offer different approaches at different times within the lifelong disease. Evaluation of patient-centred care needs to come from the patient and incorporate the impact of the condition on the individual's life. Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's *Transition: getting it right for young people.*	discharged without being given sufficient information - Inpatient survey reports consistency and coordination of care to be in the lowest 20% - Patient involvement in service improvement is poor The UK IBD audit has also found a lack of age-appropriate facilities for children and young people being treated within adult IBD services. Less than half (46%) of applicable sites indicated that they had a specific paediatric to adult transition policy. 47% had a surgeon with suitable paediatric experience and 53% had an endoscopy area with age-appropriate facilities. 71% of paediatric services (17/24) do not have formal arrangements for annual outpatient review. Only 65% provide educational opportunities for patients and their carers, and just 43% provide patients with a written care plan.	NICE Quality Standards: Patient experience in adult NHS services, QS15. NHS Constitution: The principles that guide the NHS (Page 3). Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD Standards). Specifically: - Standards A11, A12, B1, C, D British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. See also Transition in IBD (CICRA and NACC), http://www.ibdtransition.org.uk/
057	Royal College of Physicians.	Key area for quality improvement 2 **High quality**	IBD care should empower patients to understand their condition and its management. This will allow them to achieve	Whilst the UK IBD audit have demonstrated that the provision of written information about the condition is good, 10% of patients	IBD Standards: - Standard D Coulter A, Ellins J, Effectiveness of

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		patient information and support to enable informed decision making and effective self-management	the best quality of life possible within the constraints of their IBD. They should have a clear understanding of the service being offered to them and how to access support from the IBD team. Information to support decisions about medical or surgical treatments is essential. Including a discussion of both the risks and benefits. These decisions should be supported by evidence-based written information tailored to the patient's needs, including children and young people. The IBD nurse has a key role in delivering high quality information and support.	reported inadequate provision of information on discharge, a written care plan is only available in 33% and educational opportunities for patients are only available in 57% of services. Access to psychological, dietetic and specialist nursing support is at inadequate levels. Greater evaluation of information from the individual's perspective is required to ensure that this meets their requirements. Although nurse provision has improved over recent years three quarters of sites have levels of nursing support below that suggested in the IBD standards. The IBD audit found that less than half of non-electively admitted IBD patients were seen by an IBD nurse during their admission.	strategies for informing, education and involving patients, British Medical Journal, 2007; 225:24. Adams, RJ, Improving health outcomes with better patient understanding and education, Journal of Risk Management and Healthcare Policy, 2010; 3; 61-72 UK IBD audit round 3: - Organisational audit report - Inpatient care audit report
058	Royal College of Physicians.	Key area for quality improvement 3 **Pathways for rapid referral and assessment where IBD is suspected**	Rapid referral of people with suspected inflammatory bowel disease is important to avoid delay in diagnosis and increase the likelihood of early treatment initiation. Leaving active IBD untreated may have devastating effects including: poor quality of life, early surgery, malnutrition, psychosocial problems and	The IBD Standards state that: "Many patients report that their IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms. Protocols and pathways need to be agreed locally to ensure prompt referral and investigation. A communication pathway must be agreed for referral of possible IBD patients in the IBD service for rapid consultation and assessment. Such	BSG Guidelines for the management of IBD in adults, specifically: - 3.3: Diagnosis and investigation (page 5) - 4.1: Nutrition (page 7) - 7.9.1 and 7.9.2: Psychological aspects (page 29) Schoepfer AM, Dehlavi MA, Fournier N et al, Diagnostic Delay in Crohn's Disease Is Associated With a Complicated Disease Course and

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			cancers. Patients presenting with possible IBD should have a faecal calprotectin assessed and those with an elevated result should be referred for urgent investigation.	patients should be contacted within two weeks of referral and seen within four weeks, or more rapidly, if clinically necessary." The IBD Audit found that 60% of non-elective adult patients with Crohn's disease were not seen by a dietitian during their admission and only 24% of adult services have defined access to a psychologist with an interest in IBD. Only 24% of GPs stated that they were very confident in identifying the key symptoms of IBD	Increase Operation Rate, American Journal of Gastroenterology, 2013, 108; 1744-1753 NICE Diagnostic Guidance 11: Faecal Calprotectin diagnostic tests for inflammatory diseases of the bowel. UK IBD audit: - Primary care questionnaires report
059	Royal College of Physicians	Key area for quality improvement 4 **Treatment to induce and maintain steroid-free remission and long term review**	A proportion of people with IBD may normalise an unnecessarily limited pattern of life, as a result of inadequate control of symptoms, of poor medical management or anxiety about loss of bowel control. Aggressive treatment is necessary to ensure good remission, limit potential complications, the need for surgery and cancer risk and improve quality of life. Objective endpoints such as faecal calprotectin or mucosal healing should be assessed. As a reflection of this, no patient should be on steroids for more than 3 months and	The UK IBD Audit demonstrates deficits in specific aspects of provision, including access to dietetic, psychological and IBD nursing support. 60% of non-elective adult patients with Crohn's Disease were not seen by a dietitian during their admission. Only 24% of adult services have defined access to a psychologist with an interest in IBD. IBD nursing support has increased, but for 79% of adult services, this does not meet the level required to ensure cover during periods of absence. 21% of patients (664/3122) had been taking steroids for longer than 3 months continuously prior to admission.	IBD Standards: - Standard A - A11 NICE guidelines for the management of Crohn's Disease: Key priorities for implementation (page 7) NICE ulcerative colitis clinical guideline. *Methods, evidence and recommendations* states that: The number of adults with UC definitely under specialist care may not be as high as thought and may be as low as 30%". (page 16) Cairns S et al. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups. Gut 2010; 59: 666-689.' UK IBD Audit:

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			immunosuppressives and biological therapies should be widely used when necessary to control the disease. It is important that treatments are monitored In addition, all patients with IBD should have an annual review. This allows assessment of the longer term aspects of care such as cancer surveillance, anaemia, vitamin deficiencies and bone health, pain, fatigue and psychological morbidity.	only 55% of services have a register of their IBD patients Only 56% of adult services hold a joint or parallel surgical-medical clinic. 31% of patients with Crohn's disease admitted to hospital were on no treatment.	- organisational audit report - inpatient care audit report IBD Audit – "Only 10% of sites submit data to other national or international audits about IBD". BSG Guidelines Oikonomou K, Renal function and complications of inflammatory bowel disease, *Inflamm Bowel Dis.* 2011 Apr;17(4):1034-45.
060	Royal College of Physicians	Key area for quality improvement 5 **Access to appropriate specialists when needed and, specifically, within 5 working days in the event of a potential relapse**	It is important that people with IBD experiencing disease flares or possible drug-related side effects are able to obtain rapid specialist advice preventing the development of costly and potentially life-threatening complications and escalations of their disease. This is supported by the NICE guidelines for Crohn's disease and ulcerative colitis.	UK IBD Audit: - Half of GPs were unable to get their patients seen by a specialist within 7 days of relapse. - Only one third of services have a protocol in place with GPs for the shared outpatient management of IBD patients. - Only 66% of these share this with the patient, most often verbally (62%).	IBD Standards: - Standard A11 - Standard B NICE Clinical Guidelines: - 152: the management of CD - 166: UC management in adults, children & young people - 118: Surveillance for Prevention of Colorectal Cancer in People with UC, CD or Adenomas. UK IBD audit – round 3: Organisational audit report
061	Royal College of Physicians	Key area for quality improvement 6 **Multi-disciplinary team (MDT)**	The multidisciplinary team involving experienced physicians, surgeons, nurses, radiologists, pathologists, dieticians and other healthcare professional is the corner	UK IBD audit: organisational audit-round 3; - Fewer MDT meetings are taking place where both gastroenterologists and colorectal surgeons discuss	IBD Standards A1-The IBD team UK IBD audit – round 3: - inpatient care audit report - organisational audit report - inpatient experience report

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		working	stone of high quality care for individuals with complex IBD. The significant variation in the pattern and complexity of symptoms between patients, and over time in the same patient (with 50% needing surgery within 10 years of diagnosis), requires experienced and individualised clinical management with continuing collaboration between the patient and the professional team.	their patients together (79% in round 1 to 72% in round 3 of the audit). - '…a steady improvement in provision of IBD nurses but most sites remain below the level set out in the IBD Standards - Three quarters of sites have a named clinical lead - <50% of sites have a named pharmacist with only 9% having regular pharmacy input at meetings - few inpatients received any dietetic input The UK IBD audit: inpatient experience-round 3 found: - The single question that correlated most strongly with overall experience of admission was a patients rating of how well doctors and nurses worked together – confirming that good teamwork is the key to delivering a high quality experience. Just over half (56%) of sites reported offering either joint or parallel clinics.	
062	Merck Sharp and Dohme	Earlier and rapid diagnosis of IBD	There is good evidence that earlier diagnosis of IBD can drive significant improvements in the quality of life and health of patients with IBD.	Many patients report that their IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms.[1-3] When patients first present with symptoms	[1] Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD). The IBD Standards Group (2013). Available at: http://www.ibdstandards.org.uk/uploade

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				of UC or CD to their GP, rapid referral to a specialist benefits the patient by ensuring that appropriate tests are performed in a timely manner that leads to an accurate diagnosis and treatment.[2] Protocols and pathways need to be agreed locally to ensure prompt referral and investigation.[3] The BSG Guidelines state that: 'For all patients, there should be local referral patterns agreed so that patients suspected of having IBD can be referred for rapid consultation and assessment'.[4] However, 'The inaugural national report of the results for the primary care questionnaire responses' showed that in a third of cases where GPs had a consultation with the patient in the month prior to admission they did not initiate any treatment nor did they make contact with any secondary care specialists.[5]	d_files/IBDstandards.pdf Accessed 15th January 2014 [2] Reddy SI, Friedman S, Telford JJ, *et al*. Are patients with inflammatory bowel disease receiving optimal care? Am J Gastroenterol 2005; 100: 1357-61 [3] Westwood N, Travis SPI. What do IBD patients want? Aliment Pharmacol, 2008; 27 Suppl 1:1-8 [4] Mowat C, Cole A, Windsor A, Ahmad T, Arnott I, Driscoll R *et al*. Guidelines for the management of inflammatory bowel disease in adults. Gut. 2011 May; 60(5):571-607. doi: 10.1136/gut.2010.224154 [5] The inaugural national report of the results for the primary care questionnaire responses. Part of the UK inflammatory bowel disease audit 3rd round. Royal College of Physicians (2012). Available at: http://www.hqip.org.uk/assets/NCAPOP-Library/NCAPOP-2012-13/IBD-UK-Audit-Primary-Care-Questionnaire-Report-12-April-2012.pdf Accessed 15th January 2014
063	Merck Sharp and Dohme	Regular patient assessments that are appropriately recorded and considered in decision-making	The care pathway for patients with IBD is complex and it is important that disease activity and patient-reported outcome measures are monitored regularly to ensure that appropriate treatment choices	NICE clinical guidelines for CD or UC do not make clear recommendations for which assessments should be made, or their frequency, when monitoring patients with IBD, i.e. colonoscopy.[7,8] However, an	[6] Clinical Guideline 152: Crohn's disease: management in adults, children and young people. National Institute for Health and Care Excellence (2012). Available at: http://guidance.nice.org.uk/CG152 Accessed 17th January 2014

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			are being made, and that patients continue to receive therapies that manage their condition effectively. Incomplete, irregular, or lacking assessments disempower patients through obscuring information about their condition, may hamper effective decision-making around treatment choices, and may lead to patients experiencing flares which could have been anticipated through thorough and regular assessments. In order to adequately support patients throughout their treatment NICE QS15 recommends that 'Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them'. With respect to the investigations component, patients should be actively involved in the monitoring of their condition and understand the consequences for decision-making while engaged in the	objective assessment of response to therapy is an important part of using expensive medicines and the collection of disease activity scores and quality of life data is central to this. However, the completion of disease activity scores and quality of life data (EQ-5D) was found to be low at 47% and 17% respectively, in all patients with IBD.[9] The UK IBD Audit recommends that participating sites should routinely assess disease activity at baseline and again at a 3 and 12 month follow up.[8] Further, local teams should encourage patients to complete patient-reported outcome measures (EQ-5D and CCQ12) at baseline and again at a 3 and 12 month follow up, as this also forms an important part of objectively assessing response to treatment and the quality of care provided by IBD services.[9] Outcome measures should be appropriately recorded, for instance, through entering patients into the IBD Registry. Further, the frequency of assessment and adherence to scheduled assessments could be reviewed as part of the UK IBD Audit.	[7] Clinical Guideline 166: Ulcerative colitis: management in adults, children and young people. National Institute for Health and Care Excellence (2013). Available at: http://guidance.nice.org.uk/CG166 Accessed 17th January 2014 [8] National clinical audit of biological therapies: UK Inflammatory Bowel Disease (IBD) audit. Adult national report. Royal College of Physicians (2013). Available at http://www.hqip.org.uk/assets/NCAPOP-Library/NCAPOP-2013-14/National-clinical-audit-report-of-biological-therapies-Adult-report.pdf Accessed 15th January 2014 [9] Quality Standard 15: Patient experience in adult NHS services. National Institute for Health and Care Excellence (2012). Available at: http://guidance.nice.org.uk/QS15 Accessed 16th January 2014

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			care pathway.[6]		
064	Merck Sharp and Dohme	Improving the interface between primary and secondary care; Providing high quality patient-centred services	The UK IBD Audit has demonstrated significant improvements in the quality of care and service delivery for patients with IBD, underpinned by the establishment of the IBD Quality Improvement Programme and the IBD Registry. The IBD Standards group has set out those standards which healthcare providers should work to attain, which include a clear focus on 'High Quality Clinical Care' (Standard A), 'Local Delivery of Care' (Standard B), and 'Maintaining a Patient-Centred Service' (Standard C).[1] Specific standards relating to the interface and referral processes between primary and secondary care are included in, but not limited to, A11, B1, and C4.[1] In addition, NICE QS15 further supports the attainment of high quality care; Statement 12 defines the expectation for clear communication and co-ordinated care for patients between health and social care professionals.[6]	Key findings published in the IBD Standards state that improvements in care are still needed and variation in the level and quality of care remains across services.[1] The co-ordination of care and the interface between primary and secondary care were highlighted as two particular areas for improvement.[1] These findings are supported by results published in 'The inaugural national report of the results for the primary care questionnaire responses', which makes five key recommendations for improvement in both the interface between primary and secondary care healthcare professionals and the educational support that should be made available to GPs.[5]	[1] Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD). The IBD Standards Group (2013). Available at: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf Accessed 15th January 2014 [5] The inaugural national report of the results for the primary care questionnaire responses. Part of the UK inflammatory bowel disease audit 3rd round. Royal College of Physicians (2012). Available at: http://www.hqip.org.uk/assets/NCAPOP-Library/NCAPOP-2012-13/IBD-UK-Audit-Primary-Care-Questionnaire-Report-12-April-2012.pdf Accessed 15th January 2014 [6] Quality Standard 15: Patient experience in adult NHS services. National Institute for Health and Care Excellence (2012). Available at: http://guidance.nice.org.uk/QS15 Accessed 16th January 2014

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
065	Merck Sharp and Dohme	Reduced variability in transition from paediatric to adult care nationally	There is evidence to suggest that paediatric patients are managed by adult services without undergoing an effective transition process or receiving age-appropriate support. This situation is variable across the UK.	The Department of Health's good practice guidance 'Transition: getting it right for young people' advises on the transition of patients from paediatric to adult care across therapy areas, with IBD-specific recommendations on appropriate care arrangements for paediatric and transitioning patients outlined in published IBD Standards. These sources of guidance recommend that children and young people with IBD should have the choice of being managed in an age-appropriate environment.[1,10] However, results from the UK IBD Audit demonstrate that a high number of adult sites still care for patients with IBD aged 16 years and under and that, in these instances, there is an inadequate provision of essential age-appropriate supporting services.[11] Transition programs are provided by only 39%-77% of paediatric IBD centres in the UK, illustrating the current variability in service provision on a national level.[12]	[1] Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD). The IBD Standards Group (2013). Available at: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf Accessed 15th January 2014 [10] Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services. Department of Health (2006). Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132149.pdf Accessed 17th January 2014 [11] UK Inflammatory Bowel Disease Audit 3rd Round: Report of the results for the national organisational audit of paediatric inflammatory bowel disease services in the UK. Available at http://www.rcplondon.ac.uk/sites/default/files/report-of-the-results-for-the-national-organisational-audit-of_paediatric-ibd-services-in-the-uk_0.pdf Accessed 17th January 2014 [12] Philpott JR. Transitional care in inflammatory bowel disease. Gastroenterol Hepatol (N Y). 2011; 7(1): 26-32

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
066	British Dietetic Association	Key area for quality improvement 1 **As part of patient centred care all patients should have access to dietetic services**	Symptoms and signs of inflammatory bowel disease can include weight loss, low BMI, urgent and frequent diarrhoea, abdominal pain, fatigue, malaise and anaemia. Malnutrition in IBD is common and multi-factorial in origin. Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel. There should be a clear process for patients to obtain access to specialist dietetic advice. Nutritional intake and dietary advice is important when patients are admitted, when they relapse and during periods of remission [1]. During Crohn's disease relapse, diet as a primary or adjunctive treatment option can improve outcome and minimise side effects from other treatments. During relapse and remission, patients with IBD often alter their diet to alleviate symptoms but may limit the nutritional adequacy of the diet thus	Access to specialist dietetic advice is a key aspect of patient-centred care and Standard A of the IBD Standards (high quality clinical care) states access to a Dietitian should be available to all IBD patients [1]. It is at an inadequate level and there is evidence to support a lack of dietetic services in gastroenterology across the UK and the rationale for improvement [2,3]. Sixty percent of non elective adults are not seen by a Dietitian during their admission and this has not improved across all IBD audits [2]. A lack of dietetic services restricts the ability of people with IBD to be empowered to fully understand and most effectively manage their condition, given the nutritional impact of IBD. Evidence-based guidelines on the dietary management of Crohn's disease supports the use of exclusive enteral nutrition to induce disease remission followed by structured food re-introduction diets to help maintain disease remission and the role of dietary education to reduce the risk of mechanical obstruction in the presence of stricturing disease [4]. The IBD audit inpatient experience shows that just over one third of adult IBD patients reported a visit	[1] IBD Standards Update 2013. www.ibdstandards.org.uk [2] UK IBD Audit Round 3 reports http://www.rcplondon.ac.uk/projects/ibdauditround3 [3] Lomer MC, Gourgey R, Whelan K. Current practice in relation to nutritional assessment and dietary management of enteral nutrition in adults with Crohn's disease. J Hum Nutr Diet. 2013 Jun 13. doi: 10.1111/jhn.12133. [Epub ahead of print]. [4] Lee J, Allen R, Ashley S, Becker S, Cummins P, Ghadamosi A, Gooding O, Huston J, Le Couteur J, O'Sullivan D, Wilson S, Lomer MC. British Dietetic Association evidence-based guidelines for the dietary management of Crohn's disease in adults. J Hum Nutr Diet. 2013 Dec 6. doi: 10.1111/jhn.12176. [Epub ahead of print].

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			compromising their nutritional status and putting them at risk of nutritional deficiency and unintentional weight loss.	from a dietitian compared to nearly three quarters of children with IBD [2]. Local care pathways with access to dietetic services as part of the IBD team need to be accessible to patients across the boundaries of primary and secondary care.	
067	British Dietetic Association	Key area for quality improvement 2 **High quality diet and nutritional patient information and support to enable informed decision making and effective self-management**	Adults, children and young people and/or their parents or carers should be offered age-appropriate multidisciplinary support to deal with any concerns the disease and its treatment, particularly in relation to dietary considerations [1,2]. Patients should be aware of the role of the dietitian so that they can exercise treatment choice.	Patients with IBD report that nutritional problems experienced are numerous and varied and they would value specific dietary counselling [5]. Greater evaluation of nutrition and dietary information from the individual's perspective is required to ensure that this meets their requirements. Patients need to be provided with information and education including dietary considerations and therapy to support decisions and empower patients to self-manage their condition. This will help to reduce the risk of nutritional complications and symptoms.	[5] Prince A, Moosa A, Whelan K, Lomer MCE, Reidlinger D. Nutritional problems in inflammatory bowel disease: the patient perspective. J Crohn's Colitis 2011: 5(5);443-450.
068	British Dietetic Association	Key area for quality improvement 3 **All IBD patients should be screened for malnutrition**	Malnutrition and weight loss are common in patients with IBD. Weight loss is observed in up to 75% of hospitalised adult patients with active CD [1,6]. There are potentially devastating effects of delayed	From the inpatient survey of the 2010 IBD audit, one fifth of adult IBD patients rated hospital food as poor, a quarter found the food unappetising and more than one in ten reported receiving too little food or that hospital food was not	[6] ESPEN Guidelines on Enteral Nutrition: Gastroenterology Clinical Nutrition 2006: 25, 260–274. [7] NICE Clinical Guideline 32 Nutritional support in adults 2006. http://www.nice.org.uk/cg32

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			IBD diagnosis in terms of nutritional status, quality and life and possible complications. Nutritional intake and dietary advice is important when patients are admitted, when they relapse and during periods of remission [1].	suitable for their dietary needs. Results were similar for paediatrics [2]. Nutritional assessment, including body mass index (BMI) is important. The NICE guidelines for nutrition support recommend that screening for malnutrition and risk of malnutrition should be carried out on all admitted patients by healthcare professionals with appropriate skills and training [7]. There are validated tools to guide malnutrition assessment such as Malnutrition Universal Screening Tool (MUST) [8].	[8] Assessment of malnutrition http://www.bapen.org.uk/musttoolkit.html
069	British Dietetic Association	Key area for quality improvement 4 **Exclusive enteral nutrition as a primary/adjunctive treatment for active Crohn's disease**	Exclusive enteral nutrition, as a prescribed specialist liquid diet, can be used as a sole source of nutrition to induce Crohn's disease remission. It is used as primary therapy in paediatrics [6,9,10] and can achieve mucosal healing and reductions in faecal calprotectin [11]. In adults, who can adhere to the strict dietary protocol of exclusive enteral nutrition, it can be as effective as steroids and used as a primary treatment where alternative treatments are contraindicated and if offered enables increased patient choice.	The IBD Audit demonstrates deficits in specific aspects of provision, including access to dietetic support. Only 21% of patients were given exclusive enteral nutrition as a treatment in the 2010 IBD audit [2]. However, exclusive enteral nutrition has minimal side effects compared to other treatment options. Increased dietetic service provision would increase patient support to enable better adherence to exclusive enteral nutrition and potentially improve clinical outcomes. With the tendency to high relapse rate in children, it is essential to	[9] NICE Clinical Guideline 152 Crohn's disease: Management in adults, children and young people 2012. http://guidance.nice.org.uk/CG152 [10] British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK 2008. https://www.bspghan.org.uk/documents/IBDGuidelines.pdf [11] Gerasimidis K, Nikolaou CK, Edwards CA, McGrogan P. Serial fecal calprotectin changes in children with Crohn's disease on treatment with exclusive enteral nutrition: associations with disease activity, treatment response, and prediction of a clinical

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Patients of child-bearing age may wish to reduce/discontinue medications and use exclusive enteral nutrition to aid their recovery and induce remission with the on-going support of a Dietitian. A multidisciplinary approach comprising a core IBD team, including dietetics, is vital to achieving the best care for patients undertaking a course of exclusive enteral nutrition.	optimise nutritional therapy to promote growth. The use of exclusive enteral nutrition in children and adolescents with Crohn's disease has the potential to reduce the need for corticosteroid treatment, and may have a prompt effect in reducing abdominal pain due to strictures [6].	relapse. J Clin Gastroenterol. 2011: 45(3):234-9.
070	British Dietetic Association	Key area for quality improvement 5 **Dietary management of ongoing gastrointestinal symptoms in IBD**	Access to a specialist gastroenterology dietitian is key in the management of IBD as it follows an unpredictable relapsing and remitting time course with acute flare ups. During acute flare ups symptoms can include diarrhoea, abdominal pain, fatigue and anaemia which can have a detrimental effect on the patient's nutritional status. Inpatient surveys have shown malnutrition in up to 85% of patients with Crohn's disease [4,6], therefore advice on diet is one of the most pertinent issues for people with Crohn's Disease to improve clinical outcome.	Patients with IBD often alter their diet to alleviate symptoms but may limit the nutritional adequacy of the diet thus compromising their nutritional status and putting them at risk of nutritional deficiency and unintentional weight loss. For example iron deficiency anaemia, osteoporosis and vitamin D deficiency are common complications of IBD and poor dietary intake can contribute. Patients with functional symptoms and IBD may be able to improve their quality of life by receiving specialist dietetic advice on a low FODMAP diet.	[12] Camilleri, M. Managing symptoms of irritable bowel syndrome in patients with inflammatory bowel disease. Gut 2011: 60, 425–428. [13] Staudacher HM, Lomer MCE, Anderson JL, Barrett JS, Muir JG, Irving PM, Whelan K. Fermentable carbohydrate restriction impacts on luminal bifidobacteria and gastrointestinal symptoms in a randomized controlled trial of patients with irritable bowel syndrome J Nutr 2012:142(8);1510-1518. [14] Gearry RB, Irving PM, Barrett JS, Nathan DM, Shepherd SJ, Gibson PR. Reduction of dietary poorly absorbed short-chain carbohydrates (FODMAPs) improves abdominal symptoms in patients with inflammatory bowel

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			In many patients with IBD, functional gastrointestinal symptoms (e.g. abdominal pain, bloating, flatulence and diarrhoea) are more problematic than symptoms as a result of inflammation and may be attributed to irritable bowel syndrome (IBS) [12]. A diet low in short chain fermentable carbohydrates (FODMAPs) is an effective dietary intervention for IBS [13]. Furthermore, two pilot studies in patients with IBD have reported IBS-like symptom improvement [14,15]. Although evidence for the clinical effectiveness of reducing FODMAPs in IBD is limited, interest in this area is increasing.		disease-a pilot study. J Crohn's Colitis, 2009: 3(1), 8-14. [15] Croagh C, Shepherd SJ, Berryman M, et al. Pilot study on the effect of reducing dietary FODMAP intake on bowel function in patients without a colon. Inflamm Bowel Dis 2007: 13:1522–1528.
071	Crohn's and Colitis UK and Crohn's in Childhood Research Association	Key area for quality improvement 1 Patient-centred and age-appropriate care	Patient-centred and age-appropriate care is recommended within NICE guidance and the NHS Constitution and is necessary in all interactions, including diagnostics investigations, assessment, in making shared treatment decisions, inpatient care, managing treatment plans, as part of ongoing review and in the context of service development. IBD follows an unpredictable	Importance of patient-centred care The importance of patient-centred care and what it means in reality for people with IBD is shown below: "I rely a great deal on communication with my consultant and IBD nurse in finding the correct treatment and ensuring it continues to work for me. *My condition does very much affect my everyday life. For example, my symptoms have varied considerably over time according to the medication.*	This submission and evidence contained within it should be seen as supplementary to and supporting the submission from the IBD Standards Group. NICE Quality Standard 15: Patient experience in adult NHS services. NHS Constitution: "The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			relapsing and remitting course, with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her life. A lifelong condition, it most commonly first presents in the teens and twenties, with an increasing incidence of early and very early onset. When diagnosed in childhood (about 25%) of all cases), the disease is often more severe than if presenting in adulthood. The nature of IBD also carries a psychosocial impact. Education, employment, personal relationships and social and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups. Therefore, patient-centred care needs to offer different approaches at different times within the lifelong disease. Evaluation of patient-centred care needs to come from the patient and incorporate the impact of the condition on the individual’s life. Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD Standards):: “Patient-centre care should be responsive to individual needs and offer a choice of care	*When I was first diagnosed I was off work for some time and managed to return after I achieve partial remission.* *Having not endured a long commute, some of my lesser symptoms such as fatigue nevertheless increased.”* **Patients not sufficiently involved in their care** It is clear from calls to our information line that people with IBD support the evidence that there is considerable variation in the degree to which IBD services are delivering responsive, patient-centred care. Involvement of IBD patients in service planning has achieved very positive results for patient experience in specific aspects of service provision. Quality of patient-centred care can be measured through validated, patient-reported measures. Age-appropriate care Transition arrangements are inconsistent. Parents have told us that their hospitals are not willing to start a course of treatment as their child approaches 16 (but may still be some months off this date), which would overlap with the new department the child will be referred to.	Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services. IBD Standards, Standard C: Maintaining a Patent-Centred Service. http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=19 Standard D: Patient Education and Support. http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=20 RCN Inflammatory Bowel Disease Nursing Audit, http://www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf Validated patient-reported measures of experience and the impact of an individual’s condition on their quality of life should be used. See IBD Standards for examples of current measures. See IBD Standards, Standard A12 – Arrangements for the Care of Children and Young People who have IBD for details. “Paediatric and adolescent care is most appropriately undertaken by Paediatric Gastroenterologists with specialist nursing and dietetic support. These teams should operate in a managed clinical network covering a wide area, which can facilitate local shared-care arrangements with adult gastroenterology colleagues and Paediatricians who have an interest in

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			strategies where possible and appropriate" (Standard C) IBD Standards, Standard A12: All young people with IBD should be looked after in an age appropriate setting with support from professionals with suitable paediatric experience. Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people and the transition guide produced by the patient associations (Crohn's and Colitis UK and CICRA).		gastroenterology, particularly IBD, and ensure a planned transition to adult care." British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. https://www.bspghan.org.uk/documents/IBDGuidelines.pdf See also Transition in IBD (CICRA and NACC), http://www.ibdtransition.org.uk/
072	Crohn's and Colitis UK and Crohn's in Childhood Research Association	Key area for quality improvement 2 High quality patient information and support to enable informed decision making and effective self-management	IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease. They should have a clear understanding of the service being offered to them and how to access support from the IBD team. This will allow them to adapt to the social and psychological impact of IBD. Information, education and support for people with	Inconsistent provision of information and support Information and support varies considerably. Written information is important, to support informed decisions.. Crohn's and Colitis UK can provide patients with evidence based information, but they need to be able to discuss this with their specialist. Patients who were diagnosed years ago often just 'stumble' across us by chance and say 'I wish I'd known that year's ago'. They need to be signposted towards organisations such as Crohn's and Colitis UK. Importance	IBD Standards, Standard D: Patient Education and Support http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=20 Coulter A, Ellins J, Effectiveness of strategies for informing, education and involving patients, British Medical Journal, 2007; 225:24. Adams, RJ, Improving health outcomes with better patient understanding and education, Journal of Risk Management and Healthcare Policy, 2010; 3; 61-72 IBD Audit, "Sites should work to develop written care plans for patients if these do not exist, with priority given to newly diagnosed patients and those receiving

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			inflammatory bowel disease is important, in terms of discussing the effects of the condition and its course, medical treatment options, the effects of medication and the monitoring required (for example, robust safety checks in respect of immunomodulators).. Information to support decisions about surgery is also essential, both for clinicians and for people facing the possibility of surgery, including elective surgery. This includes recognising adverse prognostic factors for people admitted with acute severe colitis to enable timely decisions about escalating medical therapy or predicting the need for surgery. Good communication between healthcare professionals and patients is essential, with access to the most appropriate specialists at the appropriate time. This is facilitated by shared access to patient management plans. It should be supported by evidence-based written information tailored to the patient's needs and signposting to other sources of high quality information and support,	of information and support to patients Below are quotes from IBD patients illustrating the importance of information and support to enable effective self-management. This also demonstrates the value of access to IBD Specialist Nurses. "I had many questions before I began to take medication, so I called my IBD nurse with more than twenty questions! Despite the fact that she had limited time available, she took the time to answer every one of my questions concisely. As such, myself and my partner felt more comfortable with me beginning this new treatment." "My consultant and IBD nurse always taking the time to answer any questions I have had. This was very important for me in order to understand what is happening in my body, to have a plan going forward given that IBD is a lifelong condition and to know how to deal with this condition myself in my everyday life." Crohn's and Colitis UK produce a wide range of accredited information. We are not medically trained, but can provide information to help with discussions and make the most of the available time the patient has with their healthcare professionals.	immunomodulators and biological therapies." RCN Inflammatory Bowel Disease Nursing Audit, http://www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf J Wilburn, S P McKenna, J Twiss, K Kemp, S Campbell The Crohn's Life Impact Questionnaire (Cliq): The First Patient-Reported Outcome Measure (Prom) Specific To Crohn's Disease (Cd), Gut, available from: http://gut.bmj.com/content/62/Suppl_2/A29.1

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			especially patient organisations. Adults, children and young people and/or their parents or carers should be offered age-appropriate multidisciplinary support, including psychological support, to deal with any concerns about the disease and its treatment, including concerns about body image, living with a chronic illness and attending school and higher education. High quality, reliable patient information is highly valued by those with long-term conditions		
073	Crohn's and Colitis UK and Crohn's in Childhood Research Association	Key area for quality improvement 3 Pathways for rapid referral and specialist assessment where IBD is suspected	Rapid referral of people with suspected inflammatory bowel disease is important to avoid delay in diagnosis and increase the likelihood of early treatment initiation. Given the potentially devastating effects of delayed diagnosis in terms of quality and life and possible complications, people with these symptoms and signs and a substantially elevated faecal calprotectin level should be referred urgently for specialist assessment. All new diagnoses should be confirmed in secondary care and to have their data entered into a national registry of IBD patients. Symptoms and signs	Delayed diagnoses of IBD NICE technology appraisal for faecal calprotectin states: "A significant proportion of people with IBD (particularly children with Crohn's disease), largely because of the similarity in symptoms to those in people with non-IBD conditions, face delays in their diagnosis of up to several years," Other patients are diagnosed with IBD but given little or no information and no follow-up appointment with a consultant. Patients report that, at their appointment with their consultant, they only have a short period of time, which means that they do not have time to talk about all of the issues that are having an impact on them. Sometimes people	BSG Guidelines,"For all patients, there should be local referral patterns agreed so that patients suspected of having IBD can be referred for rapid consultation and assessment. Schoepfer AM, Dehlavi MA, Fournier N et al, Diagnostic Delay in Crohn's Disease Is Associated With a Complicated Disease Course and Increase Operation Rate, American Journal of Gastroenterology, 2013, 108; 1744-1753 NICE Diagnostic Guidance 11: Faecal Calprotectin diagnostic tests for inflammatory diseases of the bowel.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			of inflammatory bowel disease can include urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, malaise and anaemia. In some patients, there is an associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common, particularly in Crohn's disease. Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel.	have a long waiting time after their colonoscopy before having another appointment to discuss treatment and initiate it.	
074	Crohn's and Colitis UK and Crohn's in Childhood Research Association	Key area for quality improvement 4 Care and treatment to induce and maintain steroid-free remission	People with IBD should not be on steroids for more than three months. In order to achieve remission, limit potential complications and reduce cancer risk, optimal treatment must be provided. It is important that people with newly diagnosed or uncontrolled IBD are closely monitored as they undergo appropriate treatment, in order to achieve stable steroid-free remission as quickly as possible A multidisciplinary approach comprising a core IBD team, with access to essential supporting services, is vital to achieving the best care for patients. The significant variation in the pattern and complexity of	Importance of steroid free remission and regular monitoring of treatment effectiveness Callers to our information line on steroids are sometimes unclear about who to call if symptoms reappear (once the dose decreases) as no overall plan of action has been mentioned by their medical team. Importance of a multidisciplinary approach in monitoring active IBD The quote below illustrates how effective communication between health professionals is essential to ensure adequate monitoring is undertaken. 'Upon diagnosis and during times of poor results with maintenance treatments I required three courses of steroids. However I feel that the length of time I was on the third course of steroids was overlooked by my consultant and IBD nurse. I	IBD Standards – Standard A: High Quality Clinical Care. High quality, safe and integrated clinical care for IBD patients based on multidisciplinary team working and collaboration across NHS organisation structures and boundaries. NICE guidelines for the management of Crohn's Disease and Ulcerative Colitis: "Offer adults, children and young people, and/or their parents or carers, age-appropriate multidisciplinary support to deal with any concerns about the disease and its treatment, including concerns about body image, living with a chronic illness, and attending school and higher education. IBD Standards, "Immunomodulator and biological therapies must be prescribed, administered and monitored appropriately by professionals with established competence and reviewed regularly."

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			symptoms between patients, and over time in the same patient, requires experienced and individualised clinical management with continuing collaboration between the patient and the professional team. Education, employment, personal relationships and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups, and symptoms including urgency, frequency, with loss of sleep and pain and fatigue. Such symptoms can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. For understandable reasons, a proportion of people with IBD may normalise an unnecessarily limited pattern of life, as a result of inadequate control of symptoms of poor medical management or anxiety about loss of bowel control if they venture too far from familiar environments. Care and treatment therefore needs to address the wider impact of IBD for the individual patient.	requested a bone density test and was found to have early onset osteoporosis, for which I am now taking another two medications. I feel that if my steroid courses were more closely monitored and my bone density examined much earlier on that this could have been avoided.”	
075	Crohn’s and Colitis UK and Crohn's in	Key area for quality improvement 5	It is important that people with IBD experiencing disease flares or possible drug-related	Importance of treatment planning and routes back into specialist care A considerable number of callers	IBD Standards, Standard A11 – Outpatient Care: “All IBD patients who have a concern or questions about their

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Childhood Research Association	Access to appropriate specialists when needed and, specifically, within 5 working days in the event of a potential relapse	side effects are able to obtain rapid and specialist advice. This will enable them to identify and recommend appropriate action in order to prevent the development of costly and potentially life-threatening complications and escalations associated with severe disease, such as bowel perforation. The guideline for Crohn's Disease states that: "The concept that early detection of a relapse in Crohn's disease would lead to earlier treatment and therefore less severe and destructive disease is the basis for much of the long-term management of this condition." The NICE guideline for Ulcerative Colitis states that: "Close links are required to allow specialist input, rapid access to advice (especially when symptoms worsen) and coordinated monitoring of drug-side effects, and to ensure that associated issues (such as monitoring of bone density) are addressed". IBD Audit: "Recent changes within the NHS will mean more frequent movement of patients between primary and secondary care. It therefore becomes vital that protocols are in place to ensure that the	have no action plan agreed with their medical team to deal with flare-ups and call Crohn's and Colitis UK to ask if they should increase their medication. IBD Nurses are not always available or do not call back in time. People often contact Crohn's and Colitis UK with specific queries because they don't know who else to ask. Patients tell us that trying to contact their specialist team can be difficult. Patients can wait three to four months for an appointment, and appointments are often put back by months. We receive a large number of requests for dietary information when none has been given by the consultant or GP.	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. Patients experiencing a possible relapse of their IBD should have access to specialist review within a maximum of five working days." Also, IBD Standard B – Local Delivery of Care. NICE Clinical Guideline 118, Surveillance for Prevention of Colorectal Cancer in People with Ulcerative Colitis, Crohn's Disease or Adenomas. British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. https://www.bspghan.org.uk/documents/IBDGuidelines.pdf

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			necessary access to secondary care is available in a timely manner, that the appropriate follow up is undertaken and that patients should receive a written statement of their management plan. Agreed protocols between primary and secondary care will facilitate this and sites should work to establish these." Shared records: Integrated working requires shared access to essential records. IT departments should facilitate the introduction of web-based systems to enable shared entry of and access to data with enough information to enable rapid decision-making. Ideally, this will also allow patient access to support self-directed care. Inpatient surveys have shown malnutrition in up to 85% of patients with Crohn's, therefore advice on diet is a pertinent issue for people with IBD to improve clinical outcome.		
076	Crohn's and Colitis UK and Crohn's in Childhood Research Association	Key area for quality improvement 6 Annual review and monitoring	All patients with IBD should have an annual review. This is important to ensure that all aspects of the disease are under control. It provides a regular opportunity to assess	Importance of annual review Despite the clear need for ongoing support and monitoring for IBD patients, many callers to our information line do not have annual reviews and some have not had	IBD Standards – Standard A11 – Outpatient Care: "All patients with confirmed IBD should have their details maintained on the register of IBD patients even when they are no longer regularly attending outpatient clinics."

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			the patient in terms of the current management of the disease and any further support they may need in the future. In children and young people with IBD, growth and pubertal development should also be closely monitored and annual review facilitates this. In order to enable individuals to maximise their quality of life and provide appropriate levels of ongoing monitoring and surveillance, e.g. for cancer risk, anaemia, osteoporosis, liver and renal function, it is also important to prevent patients becoming lost to follow up and provide care closer to home. Annual review can be undertaken in primary care, if appropriate, but there should be specialist overview and patient records and management plans updated accordingly. Registration of all IBD patients can ensure that appropriate monitoring and surveillance is undertaken and identify when this is required. This is supported within NICE guidance in the context of biological drugs. There is an established link between IBD and an increased risk of developing cancer, primarily in the colon. The risk of	any contact with a specialist for years, despite having had several flare-ups. They appear to have fallen by wayside and then contact us to ask what they should do. We are aware of patients who have not had appropriate surveillance that went on to develop cancer. In addition to the significant case for annual review for all IBD patients in respect of potential complications and monitoring/surveillance, it is also important to ensure that individuals are managing their condition effectively and to identify any changes or additional support that may be required. This is illustrated by a patient below: “Given that IBD is a lifelong condition I know that my medication effectiveness or symptoms can change at any time so regular reviews are very important to me. When diagnosed, it took some time to find the correct treatments and even with partial remission my symptoms have varied considerably depending on life and work situations. As such, although I self-manage well, I have and still do very much rely on the advice of my consultant and IBD nurse to ensure my current medications are still working as well as they should and that they are allowing me a sufficient quality of life.”	“All IBD patients who are not under immediate or ongoing care, including those in remission, should have an annual review and basic information recorded. This may be carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken by a healthcare professional with recognised competence in IBD.” “The criteria for annual review should be agreed by the IBD team, but would normally include assessment of the need for colorectal cancer surveillance, renal function and bone densitometry.” IBD Audit – “Only 10% of sites submit data to other national or international audits about IBD”. Cairns S, Scholefield JH, Steele RJ, Dunlop MG, Thomas HJW, Evans GD, Eaden JA, Rutter MD, Atkin WP, Saunders BP, Lucassen A, Jenkins P, Fairclough PD, Woodhouse CRJ. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002). Gut 2010; 59: 666-689. Oikonomou K, Renal function and complications of inflammatory bowel disease, Inflamm Bowel Dis. 2011 Apr;17(4):1034-45. doi: 10.1002/ibd.21468. Epub 2010 Sep 14. British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. https://www.bspghan.org.uk/documents/

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			colorectal cancer increases with the extent of disease, severity of inflammation, the age of onset and duration of the disease. Colonoscopic surveillance in people at high risk of developing colorectal cancer can detect precancerous changes early on and potentially prevent progression to colorectal cancer. It can also identify invasive cancer early. Annual review provides a mechanism the identification of patients who require cancer surveillance. BSG Guidelines, "Anaemia is a common complication of IBD. Patients with IBD should have at least an annual haemoglobin check." Both osteoporosis and vitamin D deficiency (including compensated deficiency states with normal calcium and high parathyroid hormone) are common in IBD. The major risk factors for osteoporosis complicating IBD are age, steroid use and disease activity Liver biochemistry may be abnormal in up to a third of patient with defined IBD. The well-documented renal manifestations and complications of IBD, as well as the possible renal side		IBDGuidelines.pdf

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			effects of new drugs, emphasize the need for periodic evaluation of renal function.		
077	British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)	Key area for quality improvement 1 Management by a multidisciplinary IBD team	Multidisciplinary team working is an intrinsic part of an IBD service. (team structure as recommended by IBD standards 2013) Sufficient paediatric gastroenterology/nutrition nurse specialists to support inpatient care (including multidisciplinary team meetings), discharge planning and re-admission avoidance; to cover specialist clinics; ensure regional liaison, as well as perform service evaluation and development o Paediatric dietician support for inpatients (including multidisciplinary team meetings); for outpatient clinics plus regional liaison; service evaluation and development	To minimise mortality and morbidity by providing the most appropriate care for children with gastrointestinal, nutritional and liver disease To ensure shared care and clinical networks deliver good specialist care close to home through integrated pathways of care Currently the provision of MDT care for IBD in children varies.	. Reference IBD audit (paediatrics) http://www.hqip.org.uk/assets/NCAPOP-Library/Paediatric-UK-IBD-Audit-National-Report-v2-20 http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf12.pdf BSPGHAN (2008) *Guidelines for the management of inflammatory bowel disease in Children*
078	British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)	Key area for quality improvement 2 Management of children with IBD	All children, at least up to their 16th birthday, should be referred to a paediatric gastroenterology service for initial investigation and treatment. Follow up should be	Currently some children with IBD are managed by adult gastroenterology/ surgical teams. Outcomes To ensure maintenance or improvement in children's clinical	Reference IBD (paediatrics) audit http://www.hqip.org.uk/assets/NCAPOP-Library/Paediatric-UK-IBD-Audit-National-Report-v2-2012.pdf Reference IBD standards 2013

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		by paediatric teams including gastroenterologists.	provided within a paediatric gastroenterology clinical network. Children and young people with IBD should have the choice of being managed in an age-appropriate environment. In most cases, this will occur within a managed clinical network (with Age-appropriate inpatient facilities; children's nurses for all inpatient, outpatient and day case facilities) episodes	condition (in conditions where this is measurable) to enable normal activities of daily living and optimal school attendance	http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf National Service Framework (NSF) for Children and Young People in England. Care pathways are based on national standards: (http://www.doh.gov.uk/nsf/children.htm, *Bringing Networks to Life*, RCPCH) ; http://bspghan.org.uk/working_groups/documents/IBDGuidelines, http://journals.lww.com/jpgn/Fulltext/2010/02001/Guidelines for_the_Management_of_Inflammatory.1.aspx)
079	British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)	Key area for quality improvement 3 Patient education	Children with Inflammatory Bowel Disease (and their carers) should be counselled by a Paediatric Gastroenterology Clinical Nurse Specialist* before starting treatment with an immunosuppressing agent or Biologic. A network should have a minimum of 1 WTE Paediatric IBD Nurse Specialist with an identified role and competence in paediatric and adolescent IBD.	Not all children and families receive counselling by an IBD nurse before commencing immune suppressing treatment from an IBD nurse.	IBD.standards.org.uk *Available from the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) - www.bspghan.org.uk* o BSPGHAN (2005) *Guidelines for the diagnosis and management of coeliac disease in children* o BSPGHAN (2008) *Guidelines for the management of inflammatory bowel disease in Children* o BSPGHAN Report of the BSPGHAN working group to develop criteria for DGH Gastroenterology, hepatology and Nutrition Services.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Appropriate written information and support should be available for a child/young person with IBD and their family. There should be a written policy and protocol for transitional care. A named coordinator should be responsible for the preparation and oversight of transition (for example, an IBD Nurse Specialist).[52,53]		http://www.BSPGHAN.org.uk/document/DGH_SERVICES_BSPGHAN.DOC o BSPGHAN Guide for Purchasers of PGHAN Services. http://bspghan.org.uk/inforamtion/guides.shtml
080	British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)	Key area for quality improvement 4 Rapid access to a Paedaitric gastroenterology team for initial diagnosis and urgent specialist advice	Children with Inflammatory Bowel Disease (IBD) should have access to a dedicated paediatric gastroenterology clinic for all follow-up appointments within a paediatric gastroenterology clinical network. Care for IBD patients should be delivered as locally as possible, but with rapid access to more specialized services when needed. The service will offer the following care pathways and components: o Endoscopy procedures in a fully child-friendly unit with appropriate anaesthetic sessions and	There can be delays in accessing the specialized IBD service. There should be a clear process for patients to obtain access to specialist advice and support from a relevant member of the IBD team by the end of the next working day. Ideally there should be a choice of telephone and email contact. Children with Inflammatory Bowel Disease with a suspected relapse should wait no longer than 72 hours to be reviewed by the IBD service Children with suspected IBD should have access to a specialist paediatric gastroenterology service within 6 weeks of the referral being received.	IBD.standards.org.uk • BritishSocietyforGastroenterology.CareofPatientswithGastrointestinal Disorders in the UK: A Strategy for the Future, March 2006 www.bsg.org.uk/pdf_word_docs/strategy06_final.pdf Guidelines on the Management of Inflammatory Bowel Disease (IBD) in Children in the UK, October 2008. www.bspghan.org.uk/Word%20docs%20and%20 PDFs/IBDGuidelines_000.pdf http://www.commissioningboard.nhs.uk/ourwork/d-com/spec-serv/consult/ Service specification E3c

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			facilities with accredited paediatric anaesthetists, Capacity to accept emergency inpatient transfers at short notice, and admit children directly for specialist investigations without prior clinical assessment o Rapid access for the assessment and management of new referrals – inpatient, outpatient and day case o Rapid access to specialist advice as well as inpatient, outpatient and day case assessment of children managed by the specialist service o Longer term monitoring of cases through outpatient assessment (including outreach). This may be throughout childhood and adolescence for complex life-long conditions, such as IBD and intestinal failure o Prompt access to inpatient beds for the management Central to the diagnosis of IBD in children is the ready availability of urgent general anaesthetic upper GI Endoscopy and Ileocolonoscopy with	o Management is supported by a multi-disciplinary team, (MDT) – see below o Discharge processes must ensure timely and appropriate communications with services that are expected to provide other parts of the patient's pathway in compliance with national guidance The Atlas of Variation suggest a huge range in the (standardized) availability of these services across UK. Some of this variation will be down to different clinical thresholds but some variation is almost certainly to be explained by a paucity of resource. Differences are unlikely to be explained by differences in the number of children with symptoms or the incidence of organic GI disease	Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN) European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) – www.espghan.med.up.pt/joomla/ IBD working group consensus paper: Inflammatory bowel disease in children and adolescents: recommendations for diagnosis - the Porto criteria, J Pediatr. Gastroenterol. Nutr. 2005 Jul;**41**(1):1-7 *Atlas of variation* http://www.chimat.org.uk/cmo2012.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			appropriate support from skilled histopathologists Under Domain 2 of the Children's and Young People's Outcome Forum: Enhancing quality of life for people with long-term conditions, is Map 22 A and B which examines admission rates for children for upper and/or lower gastro-intestinal endoscopy per population aged 0-17 years by CCG or PCT (Directly age-standardized covering 2009/10-2011/12). .	(see http://www.chimat.org.uk/cmo2012 Low rates of GI endoscopy may reflect inadequate provision or poor access. The principle of a networked system of delivering paediatric endoscopy is a good things as will ensure: • Sustainable levels of activity that relate to local population needs; • Support for training and quality assurance; • Equity of access through common thresholds for intervention; • Rare but life-saving provision of out-of-hours interventional endoscopy in children. The formalization of paediatric networks, based on existing informal networks for the delivery of specialist children's gastroenterology services, is anticipated under the commissioning work of NHS England discussed below.	
081	British Society of Paediatric Gastroenterolo	Key area for quality improvement 5	Access to a Dietitian should be	Children with IBD should have access to a paediatric dietician and provision of psychological support	• DepartmentofHealth.NationalServiceFrameworkforChildren, YoungPeople and Maternity

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	gy Hepatology and Nutrition (BSPGHAN)	Access to Nutritional Support and Therapy and Psychological support	available to all IBD patients. All forms of nutritional therapy should be available to IBD patients, including exclusive liquid diet as therapy. A service should have a minimum of 0.5 WTE Paediatric Dietitian experienced in the use of exclusive enteral nutrition as treatment There should be Defined access (or a pathway for referral) to a Paediatric Psychologist	or counselling during admission to hospital. Timely Access is not always provided in all services. Treatment includes nutritional and psychological support for the child and their family, liaison with and support of education, and counselling on treatment and prognosis. o To ensure that children have their healthcare and any social care plans coordinated. Satisfaction from patients /parents and secondary providers seeking advice measured according to validated measure	Services, 2004. Www.gov.uk/government/publications/national- service-framework-children-young-people-and-maternity-services • UKIBDAuditSteeringGroup.UKInflammatoryBowelDiseaseAudit3rd Round: Report of the results for the national organizational audit of paediatric Inflammatory Bowel Disease services in the UK, May 2011 www.rcplondon.ac.uk/projects/ibdauditround3 • NICEClinicalGuideline112.Sedationinchildrenandyoungpeople. Www.nice.org.uk/cg112, December 2010 •
082	British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)	Effective transition from paediatric to adult services for young people	Poor transition processes are shown to lead to poor compliance and thus poor health etc. Often at a crucial time for the individual who may be going to further for higher education or starting work	Transition is an adult and apaedaitric provider issue and crosses all disciplines Many children with gastroenterological diseases have a life-long chronic disease and contact with the	• DepartmentofHealth.Transition: Gettingitrightforyoungpeople.Improving the transition of young people with long term conditions from children's to adult health services, National Service Framework for Children, Young People and Maternity Services,

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				paediatric gastroenterology service can be prolonged and intense. The service must ensure continuity of care at a senior level to achieve consistent management and adult services must engage with transition .	2006 • NACC, CICRA.TransitiontoAdultHealthcare: GuidanceforHealthProfessionals, 2008 www.ibdtransition.org.uk/downloads/IBD_Transition_Guide_Health_ Professionals.pdf •
083	Inflammatory Bowel Disease Standards Group	Key area for quality improvement 1 **Patient-centred and age-appropriate care**	Patient-centred and age-appropriate care is recommended within NICE guidance and the NHS Constitution and is necessary in all interactions, including diagnostics investigations, assessment, in making shared treatment decisions, inpatient care, managing treatment plans, as part of ongoing review and in the context of service development. IBD follows an unpredictable relapsing and remitting course, with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her life. A lifelong condition, it most commonly first presents in the teens and twenties, with	The UK IBD Audit has found considerable variation in the care of people with IBD. Although quality has improved overall in recent years, deficits still remain in particular aspects of provision relevant to patient-centred and age-appropriate care. **Patient-centred care** *Rapid access to specialist advice when needed* is a key aspect of patient-centred care. The IBD Standards state that there should be a clear process for patients to obtain access to specialist advice and support from a relevant member of the IBD team by the end of the next working day (ideally, with a choice of telephone or email contact).	This submission is informed by the IBD Standards Update 2013. www.ibdstandards.org.uk. The rationale for many of the key areas of improvement can be found in the UK IBD Audit Round 3 reports. www.rcplondon.ac.uk/projects/ibdauditround3 NICE Quality Standard 15: Patient experience in adult NHS services. NHS Constitution: "The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			an increasing incidence of early and very early onset. When diagnosed in childhood (about 25% of all cases), the disease is often more severe than if presenting in adulthood. The nature of IBD also carries a psychosocial impact. Education, employment, personal relationships and social and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups. Therefore, patient-centred care needs to offer different approaches at different times within the lifelong disease. Evaluation of patient-centred care needs to come from the patient and incorporate the impact of the condition on the individual's life. *Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD Standards)::* "Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate" (Standard C) Validated patient-reported measures of experience and the impact of an individual's	Telephone access to an IBD specialist has increased from 78% to 96% over three rounds of IBD Audit. However, this is most often provided by IBD Nurses and the majority of services do not have sufficient specialist nursing provision to run these services when cover is required, for example, during periods of sickness, training or annual leave. There is concerning evidence that *IBD inpatients are not receiving responsive, patient-centred care.* When compared with average trust scores for general inpatients (pooled scores from the National Inpatient Survey 2009), scores for adult IBD patients were in the range of the poorest 20% of trusts for consistency and coordination of care, indicating a sub-optimal experience for IBD patients in this area. 85% of adult IBD patients experienced some pain during their inpatient stay. Around a quarter reported being in pain all or most of the time. 16% rated their analgesic medication as 'not enough'. Also:	consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services." IBD Standards, Standard C: Maintaining a Patent-Centred Service. www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=19 Standard A11 – Outpatient Care "IBD patients should be able to choose from a range of options for their outpatient care. These should include attending hospital as an outpatient, guided self-management with access to support when required and care in a primary or intermediate care setting with defined links to the IBD team." www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=14 IBD Audit, Inpatient Questionnaire: "The single question that correlated most strongly with overall satisfaction was a patients rating of how well doctors and nurses worked together – confirming that good teamwork is the key to delivering a high quality experience." RCN Inflammatory Bowel Disease Nursing Audit,

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			condition on their quality of life should be used. IBD Standards, Standard A12: All young people with IBD should be looked after in an age appropriate setting with support from professionals with suitable paediatric experience. Paediatric and adolescent care is most appropriately undertaken by Paediatric Gastroenterologists with specialist nursing and dietetic support. These teams should operate in a managed clinical network covering a wide area, which can facilitate local shared-care arrangements with adult gastroenterology colleagues and Paediatricians who have an interest in gastroenterology, particularly IBD, and ensure a planned transition to adult care. Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's *Transition: getting it right for young people.*	• 13% of IBD inpatients felt that they were not involved in decisions about discharge • 13% reported insufficient notice of discharge was provided for family or someone close • 32% of patients being discharged from hospital reported no information about side effects to be aware of. • 11% reported no written information about discharge medicines. • 30% reported that no staff member had told them about danger signals to be aware of after going home. • 17% felt that they were not given enough information about how to manage their condition after discharge. • 40% reported that they did not receive a copy of the letters sent between hospital and family doctor. Furthermore, where care is subsequently shared with GPs, clearly defined arrangements are not always in place and patients are rarely provided with this information in written format. Patient involvement in service improvement	www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf See IBD Standards for examples of current validated patient-reported measures. See IBD Standards, Standard A12 – Arrangements for the Care of Children and Young People who have IBD for details. British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. www.bspghan.org.uk/documents/IBDGuidelines.pdf Transition in IBD (CICRA and NACC), www.ibdtransition.org.uk

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Patient-centred care is more likely where patients have been involved in service improvement. The percentage of services involving patients in service improvement increased from 8% in 2006 to 21% in 2010, still a very low figure. **Age-appropriate care** The IBD Audit found a lack of age-appropriate facilities for children and young people being treated within adult IBD services. Of the 39% (78/202) of adult services which look after patients aged 16 or under, less than half (46%) indicated that they had a specific paediatric to adult transition policy. A similar proportion (47%) had a surgeon with suitable paediatric experience. 53% had an endoscopy area with age-appropriate facilities, 56% had someone with training and/or extensive experience in paediatric endoscopy and 68% had an anaesthetist with paediatric training. There is also considerable scope for improvement in paediatric services. 71% of paediatric services (17/24) do not have formal arrangements for annual outpatient review. Only	

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				65% provide educational opportunities for patients and their carers, and just 43% provide patients with a written care plan. The paediatric inpatient questionnaire also found inadequate levels of recording of pubertal status and growth (25%).	
084	Inflammatory Bowel Disease Standards Group	Key area for quality improvement 2 **High quality patient information and support to enable informed decision making and effective self-management**	IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their condition. They should have a clear understanding of the service being offered to them and how to access support from the IBD team. This will allow them to adapt to the social and psychological impact of IBD. Information, education and support for people with inflammatory bowel disease is important, in terms of discussing the effects of the condition and its course, medical treatment options, the effects of medication and the monitoring required (for example, robust safety checks in respect of immunomodulators)..	In certain aspects of patient information which have been measured by the IBD Audit, there has been an improvement, for example, telephone access to an IBD specialist (90%) and services providing written information to patients with contacts in the event of a relapse (80%). **Inadequate information on discharge** However, as stated above, the third round of the IBD Audit found that a significant number of patients reported inadequate information on discharge about drug side effects and danger signs to be aware of, or how to manage their condition after going home. **Written care plans and education** A written care plan is only available	IBD Standards, Standard D: Patient Education and Support www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=20 Coulter A, Ellins J, Effectiveness of strategies for informing, education and involving patients, British Medical Journal, 2007; 225:24. Adams, RJ, Improving health outcomes with better patient understanding and education, Journal of Risk Management and Healthcare Policy, 2010; 3; 61-72 IBD Audit, “Sites should work to develop written care plans for patients if these do not exist, with priority given to newly diagnosed patients and those receiving immunomodulators and biological therapies.” The IBD Registry can support effective coordinated care by facilitating shared access to up-to-date information. RCN Inflammatory Bowel Disease

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Information to support decisions about surgery is also essential, both for clinicians and for people facing the possibility of surgery, including elective surgery. This includes recognising adverse prognostic factors for people admitted with acute severe colitis to enable timely decisions about escalating medical therapy or predicting the need for surgery. Good communication between healthcare professionals and patients is essential, with access to the most appropriate specialists at the appropriate time. This is facilitated by shared access to patient management plans. It should be supported by evidence-based written information tailored to the patient's needs and signposting to other sources of high quality information and support, especially patient organisations. Adults, children and young people and/or their parents or carers should be offered age-appropriate multidisciplinary support to deal with any	in 33% of services and formal educational opportunities for patients are only available in 57% of services. **Access to specialist support for self-management** The IBD Audit has also found that access to psychological, dietetic and specialist nursing support is at inadequate levels. This restricts the ability of people with IBD to be empowered to fully understand and most effectively manage their condition, given the psychosocial and nutritional impact of IBD. IBD Nurses are central to the provision of information, education and support for patients, for example, through helplines, clinics and email contact. However, two thirds of IBD nurse specialist services are suspended or partially suspended when the IBD nurse specialist is away. The majority do not meet the standard of 1.5 WTE IBD Nurse per 250,000 population. There is a wide range of information available, in particular via the internet. This can be helpful, where the information is of high quality and endorsed or produced by organisations with the relevant expertise and appropriate	Nursing Audit, www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf The Information Standard is a certification programme commissioned by NHS England for all organisations producing evidence-based health and care information for the public. Any organisation achieving The Information Standard has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up-to-date. www.theinformationstandard.org

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			concerns about the disease and its treatment, including concerns about body image, living with a chronic illness and attending school and higher education.	accreditation (for example, The Information Standard) as providers of information in this area, such as Crohn's and Colitis UK and the British Society of Gastroenterology. However, there are also many unregulated sites, where the information provided may be misleading and inaccurate. There is an important role for health professionals to offer advice and guidance on sources of information, signposting and to directly provide this, where possible (for example, newly diagnosed patient packs produced by Crohn's and Colitis UK). *Information about shared care arrangements* The third round of the IBD Audit found that only one third of services have a protocol in place with GPs for the shared outpatient management of IBD patients. Of these services, only 66% share this with the patient, most often verbally (62%). Greater evaluation of information from the individual's perspective is required to ensure that this meets their requirements.	
085	Inflammatory Bowel Disease	Key area for quality	Rapid referral of people with suspected inflammatory bowel	The IBD Standards state that: "Many patients report that their IBD	Guidelines for the management of inflammatory bowel disease in adults,

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Standards Group	improvement 3 **Pathways for rapid referral and specialist assessment where IBD is suspected**	disease is important to avoid delay in diagnosis and increase the likelihood of early treatment initiation. Given the potentially devastating effects of delayed diagnosis in terms of quality and life and possible complications, people with these symptoms and signs and a substantially elevated faecal calprotectin level should be referred urgently for specialist assessment. Age of diagnosis and a family history of IBD should be included in the assessment/identification of potential patients with IBD. GPs should be prepared to periodically review their diagnosis in patients with unresponsive, atypical or troublesome abdominal symptoms. All new diagnoses of IBD should be confirmed in secondary care and new patients, prospectively, should have their data entered into the National Registry. Symptoms and signs of inflammatory bowel disease can include urgent and	diagnosis was only made after long periods of coping with difficult and distressing symptoms." There is local variation in the use of faecal calprotectin and referral protocols. Only 24% of GPs felt "very confident" in recognising the key symptoms of IBD and only 6% were "very confident" in dealing with acute exacerbations of IBD. The majority of GPs, including those who were confident in recognising and dealing with IBD, expressed a desire for educational support and management in IBD. Over 40% of GPs found lines of communication with secondary care to be slow and over 10% did not always know who to contact.	British Society of Gastroenterology, 2010 (BSG Guidelines), "For all patients, there should be local referral patterns agreed so that patients suspected of having IBD can be referred for rapid consultation and assessment." Schoepfer AM, Dehlavi MA, Fournier N et al, Diagnostic Delay in Crohn's Disease Is Associated With a Complicated Disease Course and Increase Operation Rate, American Journal of Gastroenterology, 2013, 108; 1744-1753 NICE Diagnostic Guidance 11: Faecal Calprotectin diagnostic tests for inflammatory diseases of the bowel. BSG Guidelines: "Malnutrition in IBD is common and multi-factorial in origin. Nutritional assessment, including BMI is important: there are validated tools such as Malnutrition Universal Screening Tool (MUST) to guide assessment,50 (http://www.bapen.org.uk/musttoolkit.html (last accessed Oct 2010))."

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			frequent diarrhoea, rectal bleeding, pain, profound fatigue, malaise and anaemia. In some patients, there is an associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common, particularly in Crohn's disease. Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel. Given the nutritional and psychosocial impact of IBD, nutritional, psychological and quality of life assessment is essential.		
086	Inflammatory Bowel Disease Standards Group	Key area for quality improvement 4 **Care and treatment to induce and maintain steroid-free remission**	No patient should be on steroids for more than 3 months. Aggressive treatment is necessary to ensure a good remission is achieved, limit potential complications and cancer risk, and improve quality of life. Objective endpoints such as faecal calprotectin or mucosal healing are useful adjuncts to clinical assessment. It is important that people with newly diagnosed or uncontrolled IBD are closely monitored as they undergo appropriate treatment, in order	The IBD Audit has found reduced mortality rates for both Crohn's disease and Ulcerative Colitis during admission and readmission rates have lowered. This suggests improvement in the quality of care overall. However, 21% of patients (664/3122) had been taking steroids for longer than 3 months continuously prior to admission. Additionally, as stated above, the IBD Audit demonstrates deficits in specific aspects of provision, including access to dietetic, psychological and IBD nursing	IBD Standards – Standard A: High Quality Clinical Care. High quality, safe and integrated clinical care for IBD patients based on multidisciplinary team working and collaboration across NHS organisation structures and boundaries. www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf#page=14 NICE guidelines for the management of Crohn's Disease and Ulcerative Colitis: "Offer adults, children and young people, and/or their parents or carers, age-appropriate multidisciplinary support to deal with any concerns about the disease and its treatment, including concerns about body image, living with a chronic illness, and attending school and

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			to achieve stable steroid-free remission as quickly as possible. A multidisciplinary approach comprising a core IBD team, with access to essential supporting services, is vital to achieving the best care for patients. The significant variation in the pattern and complexity of symptoms between patients, and over time in the same patient, requires experienced and individualised clinical management with continuing collaboration between the patient and the professional team. Given that more than 50% of patients with Crohn's Disease will undergo surgery within 10 years of diagnosis and lifetime surgery rates are about 20-30%, patients should have access to a joint or parallel medical-surgical clinic and/or multidisciplinary team that meets the IBD standards. Evidence-based guidelines on the dietary management of Crohn's disease supports the use of enteral nutrition to induce disease remission	support. Multidisciplinary working is found in three quarters of services, but this must be improved and extended. 60% of non-elective adult patients with Crohn's Disease were not seen by a dietitian during their admission. Only 24% of adult services have defined access to a psychologist with an interest in IBD. IBD nursing support has increased, but for 79% of adult services, this does not meet the level required to ensure cover during periods of absence. A named pharmacist is part of the IBD team in only 50% of sites, with only 9% of IBD team meetings having regular pharmacy input. Only 56% of adult services hold a joint or parallel surgical-medical clinic. More evaluation is needed to determine outcomes in terms of duration of remission and mucosal healing as well as quality of life. This will require improved systems for data collection and use of registries, as specified in the IBD Standards. However, the IBD Audit found that only 55% of services have a	higher education. IBD Standards, "Immunomodulator and biological therapies must be prescribed, administered and monitored appropriately by professionals with established competence and reviewed regularly." Further evidence to support lack of dietetic services in gastroenterology across the UK: Lomer MC, Gourgey R, Whelan K. Current practice in relation to nutritional assessment and dietary management of enteral nutrition in adults with Crohn's disease. J Hum Nutr Diet. 2013 Jun 13. doi: 10.1111/jhn.12133. [Epub ahead of print] Lee J, Allen R, Ashley S, Becker S, Cummins P, Ghadamosi A, Gooding O, Huston J, Le Couteur J, O'Sullivan D, Wilson S, Lomer MC. British Dietetic Association evidence-based guidelines for the dietary management of Crohn's disease in adults. J Hum Nutr Diet. 2013 Dec 6. doi: 10.1111/jhn.12176. [Epub ahead of print] IBS in IBD Camilleri, M. (2011) Managing symptoms of irritable bowel syndrome in patients with inflammatory bowel disease. Gut 60, 425–428. Use of low FODMAP diets:

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			followed by structured food re-introduction diets to help maintain disease remission and the role of dietary education to reduce the risk of mechanical obstruction in the presence of stricturing disease. Patients with active colitis may have secondary lactose intolerance and a dairy free diet may reduce gas and bloating. In many patients, functional gastrointestinal symptoms (e.g. abdominal pain, bloating, flatulence and diarrhoea) are more problematic than symptoms as a result of inflammation and may be attributed to irritable bowel syndrome (IBS) (Camilleri, 2011). A diet low in short chain fermentable carbohydrates (FODMAPs) is an effective dietary intervention for IBS (Staudacher et al 2012). Furthermore, two pilot studies in patients with IBD have reported IBS-like symptom improvement (Croagh et al 2007, Gearry et al. 2009). Although evidence for the clinical effectiveness of reducing FODMAPs in IBD is limited, interest in this area is	register of their IBD patients and even for these services, this did not usually cover all IBD patients, but specific treatment groups. Although the use of IT had widely increased, many sites did not how many patients they were treating, with 85% of sites indicating that they had to estimate this figure.	Gearry RB, Irving PM, Barrett JS, Nathan DM, Shepherd SJ, Gibson PR (2009). Reduction of dietary poorly absorbed short-chain carbohydrates (FODMAPs) improves abdominal symptoms in patients with inflammatory bowel disease-a pilot study. J Crohns Colitis, 3(1), 8-14. Croagh C, Shepherd SJ, Berryman M, et al. Pilot study on the effect of reducing dietary FODMAP intake on bowel function in patients without a colon. Inflamm Bowel Dis 2007; 13:1522–1528. RCN Inflammatory Bowel Disease Nursing Audit, www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf BSG Guidelines, “The incidence of depressive illness and anxiety is higher in IBD cohorts than control populations. Mood disorders in patients with IBD are at least in part a consequence of the IBD itself and its medical treatment, surgery including specifically colectomy and stoma formations also have psychosocial implications as do the awareness of the risk of cancer and cancer surveillance. Human and animal studies have revealed psycho-neuroimmunological mechanisms whereby stress could influence the course of IBD. Most reports indicate that stress and adverse life events may be involved in triggering relapse of IBD.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			increasing. Education, employment, personal relationships and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups. The frequent and urgent need for the toilet, together with loss of sleep and the invisible symptoms of pain and continual or profound fatigue, can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. For understandable reasons, a proportion of people with IBD may normalise an unnecessarily limited pattern of life, as a result of inadequate control of symptoms of poor medical management or anxiety about loss of bowel control if they venture too far from familiar environments. Care and treatment therefore needs to address the wider impact of IBD for the individual patient.		Behaviour-limiting exposure to stressful situations is associated with reduced symptomatic relapse, at least in Crohn's Disease."
087	Inflammatory Bowel Disease Standards Group	Key area for quality improvement 5 **Access to appropriate specialists when**	It is important that people with IBD experiencing disease flares or possible drug-related side effects are able to obtain rapid and specialist advice. This will enable them to	As described above, improvement is needed to ensure patients are informed fully about drug side effects and effective self-management and have access to appropriate specialist advice, e.g.	IBD Standards, Standard A11 – Outpatient Care: "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

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		needed and, specifically, within 5 working days in the event of a potential relapse	identify and recommend appropriate action in order to prevent the development of costly and potentially life-threatening complications and escalations associated with severe disease, such as bowel perforation. The guideline for Crohn's Disease states that: "The concept that early detection of a relapse in Crohn's disease would lead to earlier treatment and therefore less severe and destructive disease is the basis for much of the long-term management of this condition." The NICE guideline for Ulcerative Colitis states that: "Close links are required to allow specialist input, rapid access to advice (especially when symptoms worsen) and coordinated monitoring of drug-side effects, and to ensure that associated issues (such as monitoring of bone density) are addressed". IBD Audit: "Recent changes within the NHS will mean more frequent movement of patients between primary and secondary care. It therefore becomes vital that protocols	via telephone or email, where they have concerns. This is particularly important given the plethora of questionable information available online also mentioned above. Rapid access to specialist advice is often through a telephone helpline. As highlighted above, this is compromised by insufficient IBD nursing support where services do not meet the recommended levels. Additionally, the UK IBD Audit found that around half of GPs were unable to get their patients seen by a specialist within 7 days in the event of a flare-up of their condition. This was despite reporting from hospitals that they could support specialist review within this timeframe. GPs attributed this, in many cases, to slow lines of communication and not knowing who to contact, underlining the importance of more coordinated care. This is especially important given the move towards providing care closer to home for those with long-term conditions The IBD Standards support care for IBD patients which is delivered as locally as possible but with rapid access to more specialised services when needed. However, the IBD Audit found that	facility providing a response by the end of the next working day. Patients experiencing a possible relapse of their IBD should have access to specialist review within a maximum of five working days." Also, IBD Standard B – Local Delivery of Care. NICE Clinical Guideline 118, Surveillance for Prevention of Colorectal Cancer in People with Ulcerative Colitis, Crohn's Disease or Adenomas. The IBD Registry can support effective coordinated care and self-care by facilitating shared access to patient management plans based on up-to-date information. British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. www.bspghan.org.uk/documents/IBDGuidelines.pdf

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			are in place to ensure that the necessary access to secondary care is available in a timely manner, that the appropriate follow up is undertaken and that patients should receive a written statement of their management plan. Agreed protocols between primary and secondary care will facilitate this and sites should work to establish these." Shared records: Integrated working requires shared access to essential records. IT departments should facilitate the introduction of web-based systems to enable shared entry of and access to data with enough information to enable rapid decision-making. Ideally, this will also allow patient access to support self-directed care. Access to a specialist gastroenterology dietitian is key in the management of IBD as it follows an unpredictable relapsing and remitting time course with acute flare ups. During acute flare ups symptoms can include diarrhoea, abdominal pain, fatigue and anaemia which can	only one third of services have a protocol in place with GPs for the shared outpatient management of IBD patients. Additionally, of these services, only 66% share this with the patient, most often verbally (62%), so there is considerable scope for improvement in this area. Only 19% of IBD services used a real time data collection system to support the management of patients and enable data sharing between health professionals, and ideally with patient access, to enable fast and appropriate decision making when needed.	

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			have a detrimental effect on the patient's nutritional status. Inpatient surveys have shown malnutrition in up to 85% of patients with Crohn's disease, therefore advice on diet is one of the most pertinent issues for people with Crohn's Disease to improve clinical outcomes.		
088	Inflammatory Bowel Disease Standards Group	Key area for quality improvement 6 **Annual review and monitoring**	All patients with IBD should have an annual review. This is important to ensure that all aspects of the disease are under control. It provides a regular opportunity to holistically assess the patient in terms of the current management of the disease and any further support that may be needed in the future. In children and young people with IBD, growth and pubertal development should also be closely monitored and annual review facilitates this. In order to enable individuals to maximise their quality of life and provide appropriate levels of ongoing monitoring and surveillance, e.g. for cancer risk, anaemia, osteoporosis, liver and renal function, it is also important to prevent patients becoming lost to follow up.	The Ulcerative Colitis guideline states that: "The number of adults with ulcerative colitis definitely under specialist care may not be as high as thought and may be as low as 30%". This suggests that there are a large number of people with IBD who are unlikely to be subject to appropriate monitoring and surveillance. In clinical practice there is variation in when colonoscopic surveillance starts and how frequently it is offered to people at high risk. 71% of paediatric services (17/24) do not have formal arrangements for annual outpatient review.	IBD Standards – Standard A11 – Outpatient Care: "All patients with confirmed IBD should have their details maintained on the register of IBD patients even when they are no longer regularly attending outpatient clinics." "All IBD patients who are not under immediate or ongoing care, including those in remission, should have an annual review and basic information recorded. This may be carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken by a healthcare professional with recognised competence in IBD." "The criteria for annual review should be agreed by the IBD team, but would normally include assessment of the need for colorectal cancer surveillance, renal function and bone densitometry." IBD Audit – "Only 10% of sites submit data to other national or international audits about IBD". Cairns S, Scholefield JH, Steele

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Annual review can be undertaken in primary care, if appropriate, but there should be specialist overview and patient records and management plans updated accordingly. Registration of all IBD patients can ensure that appropriate monitoring and surveillance is undertaken and identify when this is required. This is supported within NICE guidance in the context of biological drugs. There is an established link between IBD and an increased risk of developing cancer, primarily in the colon. The risk of colorectal cancer increases with the extent of disease, severity of inflammation, the age of onset and duration of the disease. Colonoscopic surveillance in people at high risk of developing colorectal cancer can detect precancerous changes early on and potentially prevent progression to colorectal cancer. It can also identify invasive cancer early. Annual review provides a mechanism for this to be monitored.		RJ, Dunlop MG, Thomas HJW, Evans GD, Eaden JA, Rutter MD, Atkin WP, Saunders BP, Lucassen A, Jenkins P, Fairclough PD, Woodhouse CRJ. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002). Gut 2010; 59: 666-689. Oikonomou K, Renal function and complications of inflammatory bowel disease, *Inflamm Bowel Dis.* 2011 Apr;17(4):1034-45. doi: 10.1002/ibd.21468. Epub 2010 Sep 14. British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. www.bspghan.org.uk/documents/IBDGuidelines.pdf

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			BSG Guidelines, “Anaemia is a common complication of IBD. Patients with IBD should have at least an annual haemoglobin check.” Both osteoporosis and vitamin D deficiency (including compensated deficiency states with normal calcium and high parathyroid hormone) are common in IBD. The major risk factors for osteoporosis complicating IBD are age, steroid use and disease activity Liver biochemistry may be abnormal in up to a third of patient with defined IBD. The well-documented renal manifestations and complications of IBD, as well as the possible renal side effects of new drugs, emphasize the need for periodic evaluation of renal function.		
089	Inflammatory Bowel Disease Standards Group	We are concerned by the exclusion of people with indeterminate colitis from this quality standard for inflammatory bowel disease			
090	Royal College	Key area for	Patient-centred and age-	The UK IBD Audit has found	NICE Quality Standards: Patient

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	of Nursing	quality improvement 1 Patient-centred and age-appropriate care	appropriate care is recommended within NICE guidance and the NHS Constitution and is necessary in all interactions, including diagnostics investigations, assessment, in making shared treatment decisions, inpatient care, managing treatment plans, as part of ongoing review and in the context of service development. IBD follows an unpredictable relapsing and remitting course, with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her life. A lifelong condition, it most commonly first presents in the teens and twenties. The nature of IBD also carries a psychosocial impact. Education, employment, personal relationships and social and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups. Therefore, patient-centred care needs to offer different approaches at different times within the lifelong disease. Evaluation of patient-centred care needs to come from the patient and incorporate the	considerable variation in the care of people with IBD. Although quality has improved overall in recent years, deficits still remain in particular aspects of provision relevant to patient-centred and age-appropriate care. The third round of the IBD Audit found that only one third of services have a protocol in place with GPs for the shared outpatient management of IBD patients. Of these services, only 66% share this with the patient, most often verbally (62%). Rapid access to specialist advice is a key aspect of patient-centred care. The IBD Standards state that there should be a clear process for patients to obtain access to specialist advice and support from a relevant member of the IBD team by the end of the next working day (ideally, with a choice of telephone or email contact). Telephone access to an IBD specialist has increased from 78% to 96% over three rounds of IBD Audit. However, this is most often provided by IBD Nurses and the majority of services do not have sufficient specialist nursing provision to run these services when cover is required, for example, during periods of	experience in adult NHS services, QS15. NHS Constitution: "The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services. See IBD Standards, Standard C: Maintaining a Patent-Centred Service for further information. Standard A11 – Outpatient Care, also applies: "IBD patients should be able to choose from a range of options for their outpatient care. These should include attending hospital as an outpatient, guided self-management with access to support when required and care in a primary or intermediate care setting with defined links to the IBD team." IBD Standards, Standard B1: "The arrangements and scope for shared care, and the circumstances in which

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			impact of the condition on the individual's life. *Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD Standards)::* "Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate" (Standard C) Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's *Transition: getting it right for young people.* IBD Standards, Standard A12: All young people with IBD should be looked after in an age appropriate setting with support from professionals with suitable paediatric experience.	sickness, training or annual leave. 13% of IBD inpatients felt that they were not involved in decisions about discharge and 13% reported insufficient notice was provided for family or someone close. 32% of patients being discharged from hospital reported no information about side effects to watch out for. 11% reported no written information about discharge medicines. 30% reported that no staff member had told them about danger signals to watch out for after going home. 17% felt that they were not given enough information about how to manage their condition after discharge. 40% reported that they did not receive a copy of the letters sent between hospital and family doctor. On average there are four beds per toilet with 24% being mixed sex. This is below the minimum standard of one toilet per three beds. 85% of adult IBD patients experienced some pain during their inpatient stay. Around a quarter reported being in pain all or most of the time. 16% rated their analgesic medication as 'not enough'. When compared with average trust	the patient should be referred back to hospital care, must be clearly defined between the hospital staff and the GP. They must be explained verbally to the patient, and written information on this provided, using clear, straightforward and appropriate language." See also Standard D: Patient Education and Support. IBD Audit, Inpatient Questionnaire: "The single question that correlated most strongly with overall satisfaction was a patients rating of how well doctors and nurses worked together – confirming that good teamwork is the key to delivering a high quality experience." Validated patient-reported measures of experience and the impact of an individual's condition on their quality of life should be used. See IBD Standards for examples of current measures. See IBD Standards, Standard A12 – Arrangements for the Care of Children and Young People who have IBD for details. "Paediatric and adolescent care is most appropriately undertaken by Paediatric Gastroenterologists with specialist nursing and dietetic support. These teams should operate in a managed clinical network covering a wide area, which can facilitate local shared-care

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				scores for general inpatients (pooled scores from the National Inpatient Survey 2009), scores for adult IBD patients were in the range of the poorest 20% of trusts for consistency and coordination of care, indicating a sub-optimal experience for IBD patients in this area. The percentage of services involving patients in service improvement increased from 8% in 2006 to 21% in 2010, still a very low figure. The IBD Audit found a lack of age-appropriate facilities for children and young people being treated within adult IBD services. Of the 39% (78/202) of services which look after patients aged 16 or under, less than half (46%) indicated that they had a specific paediatric to adult transition policy. A similar proportion (47%) had a surgeon with suitable paediatric experience. 53% had an endoscopy area with age-appropriate facilities, 56% had someone with training and/or extensive experience in paediatric endoscopy and 68% had an anaesthetist with paediatric training. 71% of paediatric services (17/24) do not have formal arrangements	arrangements with adult gastroenterology colleagues and Paediatricians who have an interest in gastroenterology, particularly IBD, and ensure a planned transition to adult care." British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Guidelines on the Management of Inflammatory Bowel Disease in Children in the UK, October 2009. See also Transition in IBD (CICRA and NACC),http://www.ibdtransition.org.uk/

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				for annual outpatient review. Only 65% provide educational opportunities for patients and their carers, and just 43% provide patients with a written care plan. The paediatric inpatient questionnaire also found inadequate levels of recording of pubertal status and growth (25% in 2010).	
091	Royal College of Nursing	Key area for quality improvement 2 High quality patient information and support to enable informed decision making and effective self-management	IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease. They should have a clear understanding of the service being offered to them and how to access support from the IBD team. This will allow them to adapt to the social and psychological impact of IBD. Information, education and support for people with inflammatory bowel disease is important, in terms of discussing the effects of the condition and its course, medical treatment options, the effects of medication and the monitoring required.	In certain aspects of patient information which have been measured by the IBD Audit, there has been an improvement, for example, telephone access to an IBD specialist (90%) and services providing written information to patients with contacts in the event of a relapse (80%). However, as stated above, the third round of the IBD Audit found that 10% of patients reported inadequate information on discharge about drug side effects and danger signs to watch out for or how to manage their condition after going home. A written care plan is only available in 33% of services and formal educational opportunities for patients are only available in 57% of services.	See IBD Standards, Standard D: Patient Education and Support for further information. Also, Coulter A, Ellins J, Effectiveness of strategies for informing, education and involving patients, British Medical Journal, 2007; 225:24. Adams, RJ, Improving health outcomes with better patient understanding and education, Journal of Risk Management and Healthcare Policy, 2010; 3; 61-72 IBD Audit, "Sites should work to develop written care plans for patients if these do not exist, with priority given to newly diagnosed patients and those receiving immodulators and biological therapies."

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Information to support decisions about surgery is also essential, both for clinicians and for people facing the possibility of surgery, including elective surgery. This includes recognising adverse prognostic factors for people admitted with acute severe colitis to enable timely decisions about escalating medical therapy or predicting the need for surgery. Good communication between healthcare professionals and patients is essential, with access to the most appropriate specialists at the appropriate time. It should be supported by evidence-based written information tailored to the patient's needs and signposting to other sources of information and support, especially patient organisations. Adults, children and young people and/or their parents or carers should be offered age-appropriate multidisciplinary support to deal with any concerns about the disease and its treatment, including concerns about body image, living with a chronic illness and	The IBD Audit has also found that access to psychological, dietetic and specialist nursing support is at inadequate levels. This restricts the ability of people with IBD to be empowered to fully understand and most effectively manage their condition, given the psychosocial and nutritional impact of IBD. Greater evaluation of information from the individual's perspective is required to ensure that this meets their requirements.	

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			attending school and higher education.		
092	Royal College of Nursing	Key area for quality improvement 3 Pathways for rapid referral and assessment where IBD is suspected	Rapid referral of people with suspected inflammatory bowel disease is important to avoid delay in diagnosis and increase the likelihood of early treatment initiation. Given the potentially devastating effects of delayed diagnosis in terms of quality and life and possible complications, people with these symptoms and signs and a substantially elevated faecal calprotectin level should be referred urgently. Symptoms and signs of inflammatory bowel disease can include urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, malaise and anaemia. In some patients, there is an associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common, particularly in Crohn’s disease. Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel. BSG guidelines: Malnutrition in IBD is common and multi-	The IBD Standards state that: “Many patients report that their IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms. Protocols and pathways need to be agreed locally to ensure prompt referral and investigation. A communication pathway must be agreed for referral of possible IBD patients in the IBD service for rapid consultation and assessment. Such patients should be contacted within two weeks of referral and seen within four weeks, or more rapidly, if clinically necessary.” The IBD Audit has found that 60% of non-elective adult patients with Crohn’s Disease were not seen by a dietician during their admission and only 24% of adult services have defined access to a psychologist with an interest in IBD.	BSG Guidelines, “For all patients, there should be local referral patterns agreed so that patients suspected of having IBD can be referred for rapid consultation and assessment. Schoepfer Am, Dehlavi MA, Fournier N et al, Diagnostic Delay in Crohn’s Disease Is Associated With a Complicated Disease Course and Increase Operation Rate, American Journal of Gastroenterology, 2013, 108; 1744-1753 NICE Diagnostic Guidance 11: Faecal Calprotectin diagnostic tests for inflammatory diseases of the bowel.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			factorial in origin. Nutritional assessment, including BMI is important: there are validated tools such as Malnutrition Universal Screening Tool (MUST) to guide assessment,50 (http://www.bapen.org.uk/musttoolkit.html (last accessed Oct 2010)). Patients with active colitis may have secondary lactose intolerance and a dairy free diet may reduce gas and bloating (EL5, RGD). Given the psychosocial impact of IBD, psychological and quality of life assessment is also essential.BSG Guidelines, “The incidence of depressive illness and anxiety is higher in IBD cohorts than control populations. Mood disorders in patients with IBD are at least in part a consequence of the IBD itself and its medical treatment, surgery including specifically colectomy and stoma formations also have psychosocial implications as do the awareness of the risk of cancer and cancer surveillance. Human and animal studies have revealed psycho-neuro-immunological mechanisms whereby stress		

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			could influence the course of IBD. Most reports indicate that stress and adverse life events may be involved in triggering relapse of IBD. Behaviour-limiting exposure to stressful situations is associated with reduced symptomatic relapse, at least in Crohn's Disease."		
093	Royal College of Nursing	Key area for quality improvement 4 Care and treatment to induce and maintain steroid-free remission	No patient should be on steroids for more than 3 months. Aggressive treatment is necessary to ensure a good remission is achieved, limit potential complications and cancer risk and improve quality of life. Objective endpoints such as faecal calprotectin or mucosal healing are useful adjuncts to clinical assessment. It is important that people with newly diagnosed or uncontrolled IBD are closely monitored as they undergo appropriate treatment, in order to achieve stable steroid-free remission as quickly as possible A multidisciplinary approach comprising a core IBD team, with access to essential supporting services, is vital to achieving the best care for patients.	The IBD Audit has found reduced mortality rates for both Crohn's disease and Ulcerative Colitis during admission and readmission rates have lowered. This suggests improvement in the quality of care overall. However, as stated earlier, the IBD Audit demonstrates deficits in specific aspects of provision, including access to dietetic, psychological and IBD nursing support. Multidisciplinary working is found in three quarters of services, but this must be improved and extended. 60% of non-elective adult patients with Crohn's Disease were not seen by a dietician during their admission. Only 24% of adult services have defined access to a psychologist with an interest in IBD. IBD nursing support has increased, but for 79% of adult services, this does not meet the level required to	IBD Standards – Standard A: High Quality Clinical Care. High quality, safe and integrated clinical care for IBD patients based on multidisciplinary team working and collaboration across NHS organisation structures and boundaries. NICE guidelines for the management of Crohn's Disease and Ulcerative Colitis: "Offer adults, children and young people, and/or their parents or carers, age-appropriate multidisciplinary support to deal with any concerns about the disease and its treatment, including concerns about body image, living with a chronic illness, and attending school and higher education. IBD Standards, "Immunomodulator and biological therapies must be prescribed, administered and monitored appropriately by professionals with established competence and reviewed regularly."

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			The significant variation in the pattern and complexity of symptoms between patients, and over time in the same patient, requires experienced and individualised clinical management with continuing collaboration between the patient and the professional team. Given that more than 50% of patients with Crohn's Disease will undergo surgery within 10 years of diagnosis and lifetime surgery rates are about 20-30%, patients should have access to a joint or parallel medical-surgical clinic that meets the IBD standards. Education, employment, personal relationships and family life may all be disrupted by the unpredictable occurrence of IBD flare-ups. The frequent and urgent need for the toilet, together with loss of sleep and the invisible symptoms of pain and continual or profound fatigue, can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. For understandable reasons, a	ensure cover during periods of absence. A named pharmacist is part of the IBD team in only 50% of sites, with only 9% of IBD team meetings having regular pharmacy input. 21% of patients (664/3122) had been taking steroids for longer than 3 months continuously prior to admission. More evaluation is needed to determine outcomes in terms of duration of remission and mucosal healing as well as quality of life. This will require improved systems for data collection and use of registries, as specified in the IBD Standards. The IBD Audit found that only 55% of services have a register of their IBD patients and even for these services, this did not usually cover all IBD patients, but specific treatment groups. . "Although the use of IT has widely increased many sites do not know how many patients they treat, with 85% of sites indicating that they had to estimate this figure." Only 56% of adult services hold a joint or parallel surgical-medical clinic.	

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			proportion of people with IBD may normalise an unnecessarily limited pattern of life, as a result of inadequate control of symptoms of poor medical management or anxiety about loss of bowel control if they venture too far from familiar environments.		
094	Royal College of Nursing	Key area for quality improvement 5 Access to appropriate specialists when needed and, specifically, within 5working days in the event of a potential relapse	It is important that people with IBD experiencing disease flares or possible drug-related side effects are able to obtain rapid and specialist advice. This will enable them to identify and recommend appropriate action in order to prevent the development of costly and potentially life-threatening complications and escalations associated with severe disease, such as bowel perforation. The guideline for Crohn's Disease states that: "The concept that early detection of a relapse in Crohn's disease would lead to earlier treatment and therefore less severe and destructive disease is the basis for much of the long-term management of this condition." The NICE guideline for Ulcerative Colitis states that: "Close links are required to	The UK IBD Audit found that around half of GPs were unable to get their patients seen by a specialist within 7 days in the event of a flare-up of their condition. This was despite reporting from hospitals that they could support specialist review within this timeframe. GPs attributed this, in many cases, to slow lines of communication and not knowing who to contact underlining the importance of more coordinated care. This is especially important given the move towards providing care closer to home for those with long-term conditions The IBD Standards support care for IBD patients which is delivered as locally as possible but with rapid access to more specialised services when needed. However, the IBD Audit found that only one third of services have a protocol in place with GPs for the shared outpatients management of IBD patients. Additionally, of these	IBD Standards, Standard A11 – Outpatient Care: "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 answer phone facility providing a response by the end of the next working day. Patients experiencing a possible relapse of their IBD should have access to specialist review within a maximum of five working days." Also, IBD Standard B – Local Delivery of Care. NICE Clinical Guideline 118, Surveillance for Prevention of Colorectal Cancer in People with Ulcerative Colitis, Crohn's Disease or Adenomas.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			allow specialist input, rapid access to advice (especially when symptoms worsen) and coordinated monitoring of drug-side effects, and to ensure that associated issues (such as monitoring of bone density) are addressed”. IBD Audit: “Recent changes within the NHS will mean more frequent movement of patients between primary and secondary care. It therefore becomes vital that protocols are in place to ensure that the necessary access to secondary care is available in a timely manner, that the appropriate follow up is undertaken and that patients should receive a written statement of their management plan. Agreed protocols between primary and secondary care will facilitate this and sites should work to establish these.” Shared records: Integrated working requires shared access to essential records. IT departments should facilitate the introduction of web-based systems to enable shared entry of and access to data with enough information to	services, only 66% share this with the patient, most often verbally (62%), so there is considerable scope for improvement in this area. As described earlier, improvement is needed to ensure patients are informed fully about drug side effects and effective self-management and have access to appropriate specialist advice, e.g. via telephone or email, where they have concerns. Only 19% of IBD services used a real time data collection system to support the management of patients and enable data sharing between health professionals, and ideally with patient access, to enable fast and appropriate decision making when needed.	

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			enable rapid decision-making. Ideally, this will also allow patient access to support self-directed care.		
095	Royal College of Nursing	Key area for quality improvement 6 Annual review and monitoring	All patients with IBD should have an annual review. This is important to ensure that all aspects of the disease are under control. It provides a regular opportunity to holistically assess the patient in terms of the current management of the disease and any further support that may be needed in the future. In children and young people with IBD, growth and pubertal development should also be closely monitored and annual review facilitates this. In order to enable individuals to maximise their quality of life and provide appropriate levels of ongoing monitoring and surveillance, e.g. for cancer risk, anaemia, osteoporosis and renal function, it is also important to prevent patients becoming lost to follow up. There is an established link between IBD and an increased risk of developing cancer, primarily in the colon. The risk of colorectal cancer increases	The Ulcerative Colitis guideline states that: “The number of adults with ulcerative colitis definitely under specialist care may not be as high as thought and may be as low as 30%”.	IBD Standards – Standard A11 – Outpatient Care: “All patients with confirmed IBD should have their details maintained on the register of IBD patients even when they are no longer regularly attending outpatient clinics.” “All IBD patients who are not under immediate or ongoing care, including those in remission, should have an annual review and basic information recorded. This may be carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken by a healthcare professional with recognised competence in IBD.” “The criteria for annual review should be agreed by the IBD team, but would normally include assessment of the need for colorectal cancer surveillance, renal function and bone densitometry.” IBD Audit – “Only 10% of sites submit data to other national or international audits about IBD”.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			with the extent of disease, severity of inflammation, the age of onset and duration of the disease. Colonoscopic surveillance in people at high risk of developing colorectal cancer can detect precancerous changes early on and potentially prevent progression to colorectal cancer. It can also identify invasive cancer early. However, in clinical practice there is variation in when colonoscopic surveillance starts and how frequently it is offered to people at high risk. This NICE clinical guideline aims to improve the care of people with IBD or adenomas at high risk of developing colorectal cancer by making evidence-based recommendations on the use of colonoscopic surveillance. Annual review provides a mechanism for this to be monitored. BSG Guidelines, “Anaemia is a common complication of IBD. Patients with IBD should have at least an annual haemoglobin check.” Both osteoporosis and vitamin		

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			D deficiency (including compensated deficiency states with normal calcium and highparathyroid hormone) are common in IBD. The major risk factors for osteoporosis complicating IBD are age, steroid use and disease activity The well-documented renal manifestations and complications of IBD, as well as the possible renal side effects of new drugs, emphasize the need for periodic evaluation of renal function. (Oikonomou K, Renal function and complications of inflammatory bowel disease, *Inflamm Bowel Dis.* 2011 Apr;17(4):1034-45. doi: 10.1002/ibd.21468. Epub 2010 Sep 14).		
096	Patient safety function of NHS England	Key area for quality improvement 1	We have not published analysis from the National Reporting and Learning System relating specifically to inflammatory bowel disease but in general analysis of causes of death and severe harm patient safety incidents have noted cases where a diagnosis of inflammatory bowel disease 'overshadows'	Whilst we appreciate the QS is linked to the related NICE accredited evidence sources, awareness of potential safety issues for patients with multiple conditions should be acknowledged	*No additional information provided by stakeholder*

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			clinical thinking, leading to potential delay in new secondary diagnosis (e.g. cancer)		
097	Patient safety function of NHS England	Key area for quality improvement 2	Medications used for IBD are associated with patients safety incidents, especially harm from omitted or delayed steroids	Advice on omitted and delayed medication was issued by NPSA although it predated NHS Evidence accreditation of their processes	http://www.nrls.npsa.nhs.uk/alerts/?entryid45=66720