

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Inflammatory bowel disease

Output: Prioritised quality improvement areas for development.

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Contents

| | | |
|---|-----------------------------------------------------------------------------------------------------------------|----|
| 1 | Introduction | 2 |
| 2 | Overview | 2 |
| 3 | Summary of suggestions | 7 |
| 4 | Suggested improvement areas | 9 |
| | Appendix 1: Inducing remission in Crohn's disease | 48 |
| | Appendix 2: Maintaining remission in Crohn's disease | 48 |
| | Appendix 3: Inducing remission in people with mild to moderate ulcerative colitis ... | 50 |
| | Appendix 4: Inducing remission in people with acute severe ulcerative colitis (all extents of disease) | 51 |
| | Appendix 5: Key priorities for implementation (CG152)..... | 52 |
| | Appendix 6: Key priorities for implementation (CG166)..... | 54 |

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for inflammatory bowel disease. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development sources below are included to help the Committee in considering potential statements and measures.

1.2 Development sources

The key development sources referenced in this briefing paper are:

[Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel](#). NICE diagnostics guidance 11 (2013).

[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).

2 Overview

2.1 Focus of quality standard

This quality standard will cover the management of inflammatory bowel disease – that is, Crohn's disease and ulcerative colitis – in adults, children and young people. It will not cover people with indeterminate colitis.

2.2 Definition

The two main forms of inflammatory bowel disease are Crohn's disease and ulcerative colitis. Both are chronic diseases that cause inflammation of the digestive system. Crohn's disease typically involves the distal ileum or colon but can occur anywhere in the gastrointestinal tract, whereas ulcerative colitis usually affects the rectum, and a variable extent of the colon proximal to the rectum.

In Crohn's disease inflammation of the digestive system leads to diarrhoea, abdominal pain, tiredness and weight loss. People with Crohn's disease can go for long periods with few or no symptoms (this is known as remission). But this can be followed by a period of active disease when symptoms flare up (this is sometimes called an exacerbation). Crohn's disease can be complicated by the development of intestinal obstruction, fistulae or perianal disease. Other complications include stricture, acute dilation and perforation of the gastrointestinal tract, and significant haemorrhage, particularly if the disease affects the colon. As well as these intestinal problems, the disease may be associated with abnormalities of the joints, eyes, liver and skin. Symptoms can be mild, but are sometimes severe and can have a big effect on a person's day to day life.

Symptoms of active disease or relapse of ulcerative colitis include bloody diarrhoea, an urgent need to defaecate and abdominal pain. Ulcerative colitis is a lifelong disease that is associated with significant morbidity. When symptoms are active, this is called a flare-up, a relapse or an exacerbation. These flare-ups can be followed by periods of months or even years with few or no symptoms.

2.3 *Incidence and prevalence*

Crohn's disease¹

The prevalence of Crohn's disease is 157 per 100,000 people, meaning there are currently at least 115,000 people in the UK with Crohn's disease. Up to a third of patients with Crohn's disease are diagnosed before the age of 21. The causes of Crohn's disease are widely debated. Smoking and genetic predisposition are two important factors that are likely to play a role.

Between 15% and 40% of children with Crohn's disease have growth impairment and this can result in permanently reduced final adult height. Along with growth, puberty is often delayed and there may be an opportunity to continue growing into late adolescence. Several studies have also shown a high incidence of psychological morbidity in children and young people as well as adults with Crohn's disease.

Most people with Crohn's disease lead active lives. Nevertheless, five years after onset, 15% to 20% of people are disabled by their disease to some degree.

Ulcerative colitis²

Ulcerative colitis is the most common type of inflammatory disease of the bowel. It has an incidence in the UK of approximately 10 per 100,000 people annually, and a prevalence of approximately 240 per 100,000. This amounts to around 146,000 people in the UK with a diagnosis of ulcerative colitis. The cause of ulcerative colitis

¹ Information sourced from [Crohn's disease](#). NICE clinical guideline 152 (2012)

² Information sourced from [Ulcerative colitis](#). NICE clinical guideline 166 (2013)

is unknown. It can develop at any age, but peak incidence is between the ages of 15 and 25 years, with a second, smaller peak between 55 and 65 years (although this second peak has not been universally demonstrated). The British Paediatric Surveillance Unit reported an incidence of ulcerative colitis in children aged younger than 16 years in the United Kingdom, of 1.4 per 100,000 with a greater proportion of Asian children having ulcerative colitis than other children. The median age for diagnosis of ulcerative colitis overall in this childhood cohort was 11.7 years (range 9.3 to 13.7 years).

Ulcerative colitis can affect a person's social and psychological wellbeing, particularly if poorly controlled. An estimated 50% of people with ulcerative colitis will have at least one relapse per year. About 80% of these are mild to moderate and about 20% are severe.

Approximately 25% of people with ulcerative colitis will have one or more episodes of acute severe colitis in their lifetime, with a 29% colectomy (an operation to remove all or part of the colon) rate. Although mortality rates have improved steadily over the past 30 years, acute severe colitis still has a mortality rate of up to 2%. Mortality is directly influenced by the timing of interventions, including medical therapy and colectomy. The most recent UK audit demonstrated an overall UK national mortality of 0.8%.

Ulcerative colitis has a well-documented association with the development of colorectal cancer, with greatest risk in people with long-standing and extensive disease. The overall lifetime risk of colorectal cancer in people with ulcerative colitis is approximately 2.7%, with an annual incidence of dysplasia or cancer of between 3.7 and 5.7%.

2.4 *Management*

Treatment of Crohn's disease is largely directed at symptom relief rather than cure. Active treatment of acute disease (inducing remission) should be distinguished from preventing relapse (maintaining remission). Current management options for Crohn's disease include drug therapy, attention to nutrition, smoking cessation and, in severe or chronic active disease, surgery.

The treatment chosen for active ulcerative colitis is likely to depend on clinical severity, extent of disease and the person's preference, and may include the use of aminosalicylates, corticosteroids or biological drugs. These drugs can be oral or topical (into the rectum), and corticosteroids may be administered intravenously in people with acute severe disease. Surgery may be considered as emergency treatment for severe ulcerative colitis that does not respond to drug treatment. People may also choose to have elective surgery for unresponsive or frequently relapsing disease that is affecting their quality of life.

See appendices 1–4 for the associated care pathway and algorithms from NICE clinical guidelines 152 and 166.

2.5 National Outcome Frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [NHS Outcomes Framework 2014/15](#)

| Domain | Overarching indicators and improvement areas |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2 Enhancing quality of life for people with long-term conditions | <p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p>Improvement areas</p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition**</p> <p>Improving functional ability in people with long-term conditions</p> <p>2.2 Employment of people with long-term conditions** * (ASCOF 1E PHOF 1.8)</p> |
| 4 Ensuring that people have a positive experience of care | <p>Overarching indicator</p> <p>4a Patient experience of primary care (i) GP services</p> <p>4b Patient experience of hospital care</p> <p>Improvement areas</p> <p>Improving hospitals’ responsiveness to personal needs</p> <p>4.2 Responsiveness to in-patients’ personal needs</p> <p>Improving children and young people’s experience of healthcare</p> <p>4.8 Children and young people’s experience of outpatient services</p> <p>Improving people’s experience of integrated care</p> <p>4.9 People’s experience of integrated care (ASCOF 3E**)</p> |
| <p>Alignment across the health and social care system</p> <p>* Indicator shared with Public Health Outcomes Framework (PHOF)</p> <p>** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)</p> | |

Table 2 [Public health outcomes framework for England, 2013–2016](#)

| Domain | Objectives and indicators |
|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 Improving the wider determinants of health | Objective Improvements against wider factors that affect health and wellbeing and health inequalities Indicators 1.3 Pupil absence |
| 2 Health improvement | Objective People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities Indicators Self-reported wellbeing |

3 Summary of suggestions

3.1 Responses

In total 17 stakeholders responded to the 2-week engagement exercise (03/01/2014–17/01/2014) and two stakeholders submitted a ‘no comment’ response. Suggestions were also provided by specialist committee members.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The Committee is asked to note that broader comments outside the remit of the quality standard development process have not been summarised. The responses have been merged and summarised in table 3 for further consideration by the Committee.

Full details on the suggestions provided are given in a separate table.

Table 3 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Diagnosis and assessment <ul style="list-style-type: none"> • Rapid referral for diagnosis • Accuracy and speed of diagnosis | <ul style="list-style-type: none"> • SCM 3, BSPGHAN, UKCPA, RCP, CCUK and CICRA, IBD Standards Group, MSD, SCM 6, RCN • RCPPath, ACB, BSPGHAN |
| Monitoring | <ul style="list-style-type: none"> • RCP, CCUK and CICRA, IBD Standards Group, ACB, BSPGHAN, SCM 1, SCM 3, SCM 4, SCM 6, MSD, BDA, QEHB, Vifor, RCN, NHS England PSD |
| Children and young people <ul style="list-style-type: none"> • Age-appropriate care • Transition from children’s to adult services | <ul style="list-style-type: none"> • ACB, BDA, BSPGHAN, RCP, CCUK and CICRA, IBD Standards Group, SCM 6, MSD, UKCPA, RCN • RCP, IBD Standards Group, SCM 3, , CCUK and CICRA, ACB, MSD, BSPGHAN, NHS England, RCN |
| Surgery <ul style="list-style-type: none"> • Prior to surgery • Specialist surgical settings and staff | <ul style="list-style-type: none"> • SCM 2, CCUK and CICRA, RCN, IBD Standards Group • SCMs 2 and 5, IBD Standards Group, RCN |

| Suggested area for improvement | Stakeholders |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Treatment</p> <ul style="list-style-type: none"> • Exclusive enteral nutrition as primary treatment for Crohn's disease • Drug treatment • Rapid referral for relapse • Co-ordination of care | <ul style="list-style-type: none"> • BDA, IBD Standards Group, SCM 4 • SCM 2, Dr Falk, ACB, RCP, UKCPA, CCUK and CICRA, IBD Standards Group, RCN, NHS England PSD • SCM 6, UKCPA, RCP, CCUK and CICRA, IBD Standards Group, RCN • CCUK and CICRA, IBD Standards Group, ACB, NHS England, SCM 3, SCM 5, SCM 6, RCP, BDA, , BSPGHAN, MSD, RCN |
| <p>Patient education, information and support</p> <ul style="list-style-type: none"> • Dietetic support • Psychological support • Information and support • IBD nurse | <ul style="list-style-type: none"> • SCMs 4 and 6, BDA, RCP, BSPGHAN, RCN • SCM 6, RCP, CCUK and CICRA, BSPGHAN, IBD Standards Group, RCN • NHS England, BSPGHAN, IBD Standards Group, SCM 1, Dr Falk, SCM 6, UKCPA, RCP, CCUK and CICRA, BDA, RCN • RCP, CCUK and CICRA, BSPGHAN, IBD Standards Group, SCM 2, RCN |
| <p>Additional area Screening admitted patients for malnutrition</p> | <ul style="list-style-type: none"> • SCM 4, BDA |
| <p>ACB, Association for Clinical Biochemistry and Laboratory Medicine BDA, British Dietetic Association BSPGHAN, British Society of Paediatric Gastroenterology, Hepatology and Nutrition CCUK and CICRA, Crohn's and Colitis UK and Crohn's in Childhood Research Association Dr Falk, Dr Falk Pharma UK Ltd. IBD Standards Group, Inflammatory Bowel Disease Standards Group MSD, Merck Sharp and Dohme NHS England NHS England PSD, NHS England Patient Safety Division QEHB, Queen Elizabeth Hospital Birmingham RCN, Royal College of Nursing RCP, Royal College of Physicians RCPPath, Royal College of Pathologists SCM, Specialist Committee Member UKCPA, UK Clinical Pharmacy Association Vifor, Vifor Pharma UK Ltd</p> | |

4 Suggested improvement areas

4.1 *Diagnosis and Assessment*

4.1.1 Summary of suggestions

Rapid referral for diagnosis

Stakeholders highlighted the need for rapid referral for suspected IBD to avoid delay in diagnosis and trigger early treatment initiation. Delayed diagnosis can have dramatic effects, including serious and rapid onset of complications and a substantial impact on the patient's quality of life. It was raised that for many patients IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms. Local protocols and pathways to ensure prompt referral and investigation for people with signs and symptoms of IBD and urgent referral of patients with substantially elevated faecal calprotectin levels were suggested. GPs' lack of confidence in identifying the key symptoms of IBD was raised.

Rapid access to paediatric gastroenterology services and the ready availability of urgent general anaesthetic upper GI endoscopy and ileocolonoscopy were specifically mentioned for children and young people with suspected IBD.

Accuracy and speed of diagnosis

Elements identified as important in providing accurate and timely diagnosis were:

- reporting of biopsies and resections to confirm diagnoses of IBD
- subclassification of Crohn's disease or ulcerative colitis (UC)
- detection of dysplasia
- exclusion of co-existent conditions
- input of a histopathologist to improve assessment of cases that are difficult to classify
- increased diagnostic accuracy of multiple site rather than single site colonoscopic biopsies
- improved interaction between clinicians and pathologists.

4.1.2 Selected recommendations from development sources

Table 4 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

| Suggested quality improvement area | Suggested source guidance recommendations |
|-------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Rapid referral for diagnosis | <p>Diagnosis and investigation Guidelines for the management of inflammatory bowel disease in adults, Section 3.3 Diagnosis and investigation p7</p> <p>Management of ulcerative colitis Guidelines for the management of inflammatory bowel disease in adults, Section 5.3 Acute severe ulcerative colitis p17</p> |
| Accuracy and speed of diagnosis | <p>Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel NICE DG11 Recommendation 1.1 NICE DG11 Recommendation 1.2</p> <p>Endoscopy Guidelines for the management of inflammatory bowel disease in adults 3.3.3</p> <p>Histopathology Guidelines for the management of inflammatory bowel disease in adults 3.4</p> <p>Diagnosis and investigation Guidelines for the management of inflammatory bowel disease in adults, Section 3.3 Diagnosis and investigation, p7</p> <p>Management of ulcerative colitis Guidelines for the management of inflammatory bowel disease in adults, Section 5.3 Acute severe ulcerative colitis p18</p> |

Rapid referral for diagnosis

Diagnosis and investigation

Guidelines for the management of inflammatory bowel disease in adults, Section 3.3 Diagnosis and investigation p7

- Local guidelines/referral pathways should be in place for rapid referral of new/suspected cases of IBD.
- Outpatients should wait no more than 4 weeks for radiological/ endoscopic investigations.
- Inpatients with severe disease should wait no more than 24 h for necessary imaging or endoscopy.

Management of ulcerative colitis

Guidelines for the management of inflammatory bowel disease in adults, Section 5.3

Patients admitted with known or suspected IBD should be discussed with and normally be transferred to the care of a consultant gastroenterologist/colorectal surgeon within 24 h of admission.

Accuracy and speed of diagnosis

Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel

NICE DG11 Recommendation 1.1

Faecal calprotectin testing is recommended as an option to support clinicians with the differential diagnosis of inflammatory bowel disease (IBD) or irritable bowel syndrome (IBS) in adults with recent onset lower gastrointestinal symptoms for whom specialist assessment is being considered, if:

- cancer is not suspected, having considered the risk factors (for example, age) described in [Referral guidelines for suspected cancer](#) (NICE clinical guideline 27), **and**
- appropriate quality assurance processes and locally agreed care pathways are in place for the testing.

NICE DG11 Recommendation 1.2

Faecal calprotectin testing is recommended as an option to support clinicians with the differential diagnosis of IBD or non-IBD (including IBS) in children with suspected IBD who have been referred for specialist assessment, if:

- appropriate quality assurance processes and locally agreed care pathways are in place for the testing.

Endoscopy

Guidelines for the management of inflammatory bowel disease in adults 3.3.3

Colonoscopy with multiple biopsies (at least two biopsies from five sites including the distal ileum and rectum) is the first line procedure for diagnosing colitis. It allows

classification of disease based on endoscopic extent, severity of mucosal disease and histological features. It also allows assessment of suspected stenoses in the distal ileum or colon.

Histopathology

Guidelines for the management of inflammatory bowel disease in adults 3.4

Histopathological examination of biopsy specimens should be carried out according to the BSG guideline, 'A Structured Approach to Colorectal Biopsy Assessment'. There should be an attempt to define the type of IBD, to mention other coexistent diagnoses or complications and to mention the absence or presence of any dysplasia and its grade. The appropriate term for IBD that cannot be classified is 'IBD Unclassified'. Medical and surgical therapy may modify the histological appearances of IBD and these should be taken into account when assessing IBD biopsy pathology.

Diagnosis and investigation

Guidelines for the management of inflammatory bowel disease in adults, Section 3.3 Diagnosis and investigation, p7 paragraph 4, bullet point 5

Processing of biopsies should be rapid (2-5 days maximum according to need).

Management of ulcerative colitis

Guidelines for the management of inflammatory bowel disease in adults, Section 5.3 Acute severe ulcerative colitis p18

Flexible sigmoidoscopy and biopsy should be available within 72 h (ideally within 24h) and a histological diagnosis within 5 days to confirm diagnosis and exclude CMV. (IBD Standard A9)

4.1.3 Current UK practice

Rapid referral for diagnosis

The UK IBD primary care questionnaire³ reports that only 24% of GPs indicated that they were very confident in recognising the key symptoms of IBD, with 8.3% being slightly confident, 67.3% being somewhat confident and 0.3% not confident. 80.7% of respondents felt they needed educational support in the management of IBD. Additionally, in response to a question regarding problems accessing the appropriate help/access to secondary care 8.2% of GPs don't know who to contact in relation to

³ Royal College of Physicians (2012) The inaugural national report of the results for the primary care questionnaire responses - Part of the UK inflammatory bowel disease audit 3rd round

IBD, 44.7% said they know who to contact but lines of communication are slow, 30.8% have no problems and 4.5% don't know what the problems are.

Rates of paediatric endoscopy per 100,000 population aged 0-17 years (2009-12)⁴ vary across the country, with the lowest being 32.7 per 100,000 and the highest 237.1. Whilst some of this variation will be down to different clinical thresholds it might also reflect inadequate provision or poor access.

A paper on patients newly diagnosed with ulcerative colitis⁵ showed that there is variation in the time that patients referred to colorectal surgery outpatients wait for disease-specific treatment initiation compared to patients referred to gastroenterology outpatients (13.8 vs 33.6 days, P=0.01).

Accuracy and speed of diagnosis

In a 2007 audit of UK pathologists' use of the British Society of Gastroenterology guidelines for the initial biopsy diagnosis of suspected chronic idiopathic IBD⁶, 11% of respondents reported there were no opportunities for clinicopathological discussion. The paper highlighted that there was considerable variation between respondents in the quality of clinical details received and in the use of the endoscopy report as a request form. Most respondents were always or usually able to ascertain the site of origin of the colorectal biopsies they received. However, 27% of respondents used the term "indeterminate colitis" when reporting biopsies and 86% when reporting resections, showing that the anatomical site of origin of IBD biopsies and resections was not always clear. Approximately 50% of respondents judged the clinical information supplied as "usually" or "always" adequate. There was also variation in the percentages who received a copy of the endoscopy report, with over 30% "rarely" receiving it.

The 2011 UK IBD Audit Report of Paediatric IBD services⁷ reported that 79% of paediatric sites said that histological reports are available within 5 working days and 83% said urgent colonic biopsies are available within 2 working days. In the 2011 UK IBD Audit Report of Adult IBD services⁸ 79% of adult sites said that histological reports are available within 5 working days and 67% said that urgent colonic biopsies are available within 2 working days. In the same audits 65% of adult sites said there

⁴ Chimat (2013) Rates of endoscopy procedures for children aged 17 years and under, directly standardised rate per 100,000 population

⁵ Ward, S.T. et al (2013) Patients newly diagnosed with ulcerative colitis receive earlier treatment in surgical clinics. *Colorectal Disease* 15, 836-841.

⁶ Feakins, R.M. (2007) An audit of UK pathologists' use of the British Society of Gastroenterology guidelines for the initial biopsy diagnosis of suspected chronic idiopathic inflammatory bowel disease. *J Clin Pathol* 2007 60: 1178-1179

⁷ Royal College of Physicians (2011) 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

⁸ Royal College of Physicians (2011) UK Inflammatory Bowel Disease Audit 3rd Round - Report of the results for the national organisational audit of adult inflammatory bowel disease services in the UK

is a named histopathologist and 75% of paediatric sites said there is a named paediatric histopathologist with an interest in gastroenterology attached to the IBD team.

4.2 **Monitoring**

4.2.1 **Summary of suggestions**

Stakeholders suggested that all patients with IBD should have an annual review to allow for assessment of the longer term aspects of care, such as cancer surveillance, anaemia, malnutrition, vitamin deficiencies and bone health. The importance of assessing for complications such as these and providing appropriate interventions when required was stated. Enabling regular opportunity to assess the patient in terms of the current management and appropriate treatment of the disease and any further support and information they may need was highlighted.

Stakeholders emphasised the role of IBD nurses in monitoring treatment and issues around insufficient numbers of nurses. The lack of formal arrangements for annual outpatient review in paediatric services and inadequate recording and monitoring of pubertal status and growth was also raised. Creation of registers for monitoring patients with IBD was suggested.

4.2.2 **Selected recommendations from development sources**

Table 5 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

| Suggested quality improvement area | Selected source guidance recommendations |
|-------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Monitoring | People with inflammatory bowel disease NICE CG118 Recommendation 1.1.1 Maintaining remission in Crohn's disease NICE CG152 Recommendation 1.3.2 Follow-up during remission for those who choose not to receive maintenance treatment NICE CG 152 Recommendation 1.3.3 Monitoring for osteopenia and assessing fracture risk NICE CG152 Recommendations 1.6.1 and 1.6.2 Monitoring bone health, adults NICE CG166 Recommendation 1.6.1 Monitoring bone health, children and young people NICE CG166 Recommendation 1.6.2 |

| | |
|--|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | <p>Monitoring growth and pubertal development in children and young people NICE CG166 Recommendations 1.6.3 and 1.6.6</p> <p>Screening for anaemia Guidelines for the management of inflammatory bowel disease in adults, Section 7.7</p> <p>Patient management (IBD Standard A4) Guidelines for the management of inflammatory bowel disease in adults p4, bullet point 6</p> |
|--|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

People with inflammatory bowel disease

NICE CG118 Recommendation 1.1.1

Offer colonoscopic surveillance to people with inflammatory bowel disease (IBD) whose symptoms started 10 years ago and who have:

- ulcerative colitis (but not proctitis alone) **or**
- Crohn's colitis involving more than one segment of colon.

Maintaining remission in Crohn's disease

NICE CG152 Recommendation 1.3.2

Offer colonoscopic surveillance in line with [Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas](#) (NICE clinical guideline 118).

Follow-up during remission for those who choose not to receive maintenance treatment

NICE CG 152 Recommendation 1.3.3

When people choose not to receive maintenance treatment:

- discuss and agree with them, and/or their parents or carers if appropriate, plans for follow-up, including the frequency of follow-up and who they should see
- ensure they know which symptoms may suggest a relapse and should prompt a consultation with their healthcare professional (most frequently, unintended weight loss, abdominal pain, diarrhoea, general ill-health)
- ensure they know how to access the healthcare system if they experience a relapse

- discuss the importance of not smoking.

Monitoring for osteopenia and assessing fracture risk

NICE CG152 Recommendations 1.6.1 and 1.6.2

Refer to the NICE clinical guideline on [Osteoporosis: assessing the risk of fragility fracture](#) (NICE clinical guideline 146) for recommendations on assessing the risk of fragility fracture in adults. Crohn's disease is a cause of secondary osteoporosis.

1.6.1 Do not routinely monitor for changes in bone mineral density in children and young people.

1.6.2 Consider monitoring for changes in bone mineral density in children and young people with risk factors, such as low body mass index (BMI), low trauma fracture or continued or repeated glucocorticosteroid use.

Monitoring bone health, adults

NICE CG166 Recommendation 1.6.1

For recommendations on assessing the risk of fragility fracture in adults, refer to [Osteoporosis: assessing the risk of fragility fracture](#) (NICE clinical guideline 146).

Monitoring bone health, children and young people

NICE CG166 Recommendation 1.6.2

Consider monitoring bone health in children and young people with ulcerative colitis in the following circumstances:

- during chronic active disease
- after treatment with systemic corticosteroids
- after recurrent active disease.

Monitoring growth and pubertal development in children and young people

NICE CG166 Recommendations 1.6.3 and 1.6.6

1.6.3 Monitor the height and body weight of children and young people with ulcerative colitis against expected values on centile charts (and/or z scores) at the following intervals according to disease activity:

- every 3–6 months:
 - if they have an inflammatory exacerbation and are approaching or undergoing puberty or
 - if there is chronic active disease or

- if they are being treated with systemic corticosteroids
- every 6 months during pubertal growth if the disease is inactive
- every 12 months if none of the criteria above are met.

1.6.6 Monitoring of growth and pubertal development:

- can be done in a range of locations (for example, at routine appointments, acute admissions or urgent appointments in primary care, community services or secondary care)
- should be carried out by appropriately trained healthcare professionals as part of the overall clinical assessment (including disease activity) to help inform the need for timely investigation, referral and/or interventions, particularly during pubertal growth.

If the young person prefers self-assessment for monitoring pubertal development, this should be facilitated where possible and they should be instructed on how to do this.

Screening for anaemia

Guidelines for the management of inflammatory bowel disease in adults, Section 7.7

Patients with IBD should have at least annual haemoglobin check. The ferritin, transferrin saturation and CRP should be checked in anaemic patients or those with low MCV. The CRP is important to interpret the ferritin level as ferritin can be elevated in an acute phase reaction. Levels of ferritin less than 100 mg/l are suggestive of iron deficiency. Those patients with small bowel disease at risk of folate or B12 malabsorption or with a macrocytosis should have levels of B12 and folate checked.

Patient management (IBD Standard A4)

Guidelines for the management of inflammatory bowel disease in adults p4, bullet point 6

All IBD outpatients should have an annual review and basic information recorded. This may be in a hospital/community clinic, or by telephone follow-up, and should be done by a healthcare professional with recognised competence in IBD (Standard A11).

4.2.3 Current UK practice

In the UK audit of adult IBD inpatient care (2012)⁹, bone protection agents were prescribed for 66% of adults with ulcerative colitis prescribed steroids on discharge and 58% of adults with Crohn's disease. 67% of adults with Crohn's disease patients taking steroids for more than 3 months continuously were also prescribed bone protection agents. In the audit of paediatric IBD inpatient care (2012)¹⁰ 27% of children and young people discharged on steroids with ulcerative colitis were prescribed bone protection agents and 21% of children and young people with Crohn's disease.

The 2011 UK IBD Audit Report of paediatric services stated that 71% of paediatric sites do not have formal arrangements for paediatric annual outpatient review. Of those that do carry out annual reviews, 100% assess height and weight, 71% include the assessment of iron studies, 71% include B12 Folate, 57% Vitamin D and 86% pubertal status in the review. However, in the audit of paediatric IBD inpatient care (2012) pubertal status was only recorded in the 12 months prior to admission (in patients aged 10 at the time of their last outpatient appointment) in 25% of patients with Crohn's disease.

The 2011 IBD audit of adult services stated that 78% of adult sites do have facilities for an annual patient review for adults and 64% include the assessment of iron studies in the review, 66% include B12 Folate, 39% Vitamin D and 98% the need for cancer surveillance.

In the 2011 audits, registers of IBD patients were kept in 55% of adult sites and 78% of paediatric sites, however the paediatric report highlights that half of the paediatric sites had to estimate when asked to identify how many IBD patients their paediatric IBD Service manages, which raises doubt over whether the existing registers are updated on a regular basis and used effectively.

Crohn's and Colitis UK and Crohn's in Childhood Research Association report that many callers to their information line do not have annual reviews and some have not had any contact with a specialist for years, despite having had several flare-ups. They state their callers appear to have fallen by the wayside and then contact them to ask what they should do. They also mention that they are aware of patients who have not had appropriate surveillance and went on to develop cancer.

⁹ Royal College of Physicians (2012) Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in the UK - Round 3.

¹⁰ Royal College of Physicians (2012) Report of the results for the national clinical audit of paediatric inflammatory bowel disease inpatient care in the UK – National Report version 2.

4.3 Children and Young People

4.3.1 Summary of suggestions

Age-appropriate care

Stakeholders mentioned the lack of age-appropriate facilities for children and young people with IBD, meaning that they are being treated in adult services, with a requirement for age-appropriate endoscopy facilities being specifically raised. Ease of access to specialist paediatric gastroenterology services for initial investigation and treatment is mentioned as an issue, as well as the need for specialist nursing and dietetic support. The need for suitable paediatric experience and training in professionals supporting children and young people with IBD, in particular surgeons, anaesthetists and endoscopists was highlighted.

Transition from children's to adult services

Stakeholders highlighted that services lack specific paediatric to adult transition policies and suggested that the care of young people with IBD 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 (2006). It was reported that as children approach the age of 16 hospitals are unwilling to start treatment that might overlap with the new department that will treat the child. The fact that transition between services often comes at a crucial time for the individual, who may be going to further or higher education or starting work, was raised. Stakeholders felt that there should be continuity of care to ensure consistent management as IBD is a lifelong disease.

4.3.2 Selected recommendations from development sources

Table 6 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

| Suggested quality improvement area | Selected source guidance recommendations |
|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Age-appropriate care | The multidisciplinary team NICE CG166 Recommendation 1.2.10 Patient information and support NICE CG152 Recommendation 1.1.6 (KPI) |
| Transition from children's to adult services | Management of adolescents (transitional care) Guidelines for the management of inflammatory bowel disease in adults, |

| | |
|--|-------------------------------------------------------|
| | Section 7.11, IBD service standard: (Standard A12) |
|--|-------------------------------------------------------|

Age-appropriate care

The multidisciplinary team

NICE CG 166 Recommendation 1.2.10

For people admitted to hospital with acute severe ulcerative colitis:

- ensure that a gastroenterologist and a colorectal surgeon collaborate to provide treatment and management
- ensure that the composition of the multidisciplinary team is appropriate for the age of the person
- seek advice from a paediatrician with expertise in gastroenterology when treating a child or young person
- ensure that the obstetric and gynaecology team is included when treating a pregnant woman.

Patient information and support

NICE CG152 Recommendations 1.1.6 (Key priority for implementation)

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.

Transition from children's to adult services

Management of adolescents (transitional care)

Guidelines for the management of inflammatory bowel disease in adults, Section 7.11, IBD service standard: (Standard A12)

- There must be a defined policy and protocol for transitional care.
- A named co-ordinator should be responsible for the preparation and oversight of transition (eg, IBD nurse specialist).

4.3.3 Current UK practice

Age-appropriate care

In the IBD audit of adult services (2011) 39% of adult sites indicated that they look after IBD patients aged 16 and under. Only 47% had a surgeon with suitable paediatric experience, 53% had an endoscopy area with age appropriate facilities, 56% had a trained/experienced paediatric endoscopist and 68% had an anaesthetist with paediatric training.

The IBD audit of paediatric services (2011) highlights that there has been a significant increase in the median number of WTE paediatric gastroenterology/IBD nurse specialists at each site, rising from 1 WTE in 2008 to 1.5 WTE in 2010. 83% of sites, compared to 61% in 2008, now have at least some provision of this service and where they do have this provision in 2010 they all meet the minimum of having 0.5 WTE specialist nursing provision, as recommended in the IBD Standards. There was also an increase from 2008 to 2010 in the median number of WTE paediatric consultant gastroenterologists (2 to 2.2), and the median number of WTE paediatric surgeons (4.5 to 5.5) and the number of sites with a designated paediatric gastroenterology ward (6/23 to 8/23).

In a paper on the requirements and barriers to transition of adolescents with IBD¹¹, 59% of paediatric gastroenterologists responded that they perceived the adequacy of training in adolescent care of their adult gastroenterology colleagues was suboptimal. Similarly 65% of the adult gastroenterology respondents acknowledged that they have received inadequate training in this area.

Transition from children's to adult services

The IBD audit of paediatric services (2011) reports that only 46% of sites that look after patients aged 16 and under indicated that they had a specific paediatric to adult transition policy.

The Crohn's and Colitis UK and Crohn's in Childhood Research Association reported that parents have told them that the hospitals treating their child are not willing to start a course of treatment that would overlap with the new department the child will be referred to as their child approaches 16, even though they may still be some months off this date.

The following issues were highlighted in the paper on the requirements and barriers to transition of adolescents with IBD:

¹¹ Sebastian S. et al (2012) The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. *Journal of Crohn's and Colitis* (2012) 6, 830–844.

- Among responding adult gastroenterologists a significant proportion (59%) was not currently involved in delivery of transition service. The reasons cited for non-involvement included the absence of such a service (40%), too few patients (18%) or because the service was run by a colleague (34%), while 6% were in the process of setting up the service.
- 58% of the paediatric gastroenterologists who responded were involved in the transition of care in their institution and the remainder were not involved due to the lack of a service (32%), because the service is run by another colleague (44%), due to being in the process of setting up the service (17%) and having too few patients (6%).
- A larger proportion of responding paediatric gastroenterologists (74, 90%) expressed interest in transition care when compared to adult gastroenterologists (236, 66%) ($p=0.05$).
- 47% (162/358) of the adult gastroenterologists and 79% of the paediatric gastroenterologists described the value of a structured and individualised transition as very important ($p=0.001$). Moderate importance was attributed to transition care by 34% and 21% of adult and paediatric gastroenterologists respectively. While 18% of adult gastroenterology respondents felt that the need for transition care is minimally and/or not important none of the paediatric gastroenterologist expressed this view.

4.4 Surgery

4.4.1 Summary of suggestions

Prior to surgery

Stakeholders stated that all patients with ulcerative colitis considering surgery should receive counselling that involves discussions with consultant gastroenterologists, colorectal surgeons, IBD nurse specialists and stoma therapists. The importance of information to support decisions about surgery, for both clinicians and people facing the possibility of surgery, including elective surgery, was highlighted. Discussing both the risks and benefits of surgery with patients was raised.

Appropriate assessment of the need for surgery for patients with acute severe ulcerative colitis was stressed.

Specialist surgical settings and staff

Stakeholders suggested that surgery for IBD should be undertaken by specialists with the appropriate skills within a unit with specialist facilities, such as facilities for laparoscopic surgery, where IBD operations are performed regularly. Joint management in an IBD unit with both gastroenterology and surgical skills was highlighted. Collecting data on caseloads and complications after surgery was also recommended.

4.4.2 Selected recommendations from development sources

Table 7 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

| Suggested quality improvement area | Selected source guidance recommendations |
|-------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Prior to surgery | <p>Managing Strictures NICE CG 152 Recommendation 1.5.4</p> <p>Information when considering surgery NICE CG 166 Recommendations 1.3.1 (KPI), 1.3.2, 1.3.3, 1.3.4, 1.3.5</p> <p>Assessing likelihood of needing surgery NICE CG 166 Recommendation 1.2.16 (KPI)</p> |
| Specialist surgical settings and staff | <p>Surgery for ulcerative colitis Guidelines for the management of inflammatory bowel disease in adults Section 5.5.3 p20</p> <p>Indications for surgery Guidelines for the management of inflammatory bowel disease in adults Section 6.6.2</p> |

Prior to surgery

Managing Strictures

NICE CG 152 Recommendation 1.5.4

Discuss the benefits and risks of balloon dilation and surgical interventions for managing strictures with:

- the person with Crohn's disease and/or their parent or carer if appropriate and
- a surgeon and
- a gastroenterologist.

Information when considering surgery

NICE CG 166 Recommendation 1.3.1 (Key priority for implementation)

For people with ulcerative colitis who are considering surgery, ensure that a specialist (such as a gastroenterologist or a nurse specialist) gives the person (and their family members or carers as appropriate) information about all available treatment options, and discusses this with them. Information should include the benefits and risks of the different treatments and the potential consequences of no treatment.

NICE CG 166 Recommendation 1.3.2

Ensure that the person (and their family members or carers as appropriate) has sufficient time and opportunities to think about the options and the implications of the different treatments.

NICE CG 166 Recommendation 1.3.3

Ensure that a colorectal surgeon gives any person who is considering surgery (and their family members or carers as appropriate) specific information about what they can expect in the short and long term after surgery, and discusses this with them.

NICE CG 166 Recommendation 1.3.4

Ensure that a specialist (such as a colorectal surgeon, a gastroenterologist, an inflammatory bowel disease nurse specialist or a stoma nurse) gives any person who is considering surgery (and their family members or carers as appropriate) information about:

- diet
- sensitive topics such as sexual function
- effects on lifestyle
- psychological wellbeing
- the type of surgery, the possibility of needing a stoma and stoma care.

NICE CG 166 Recommendation 1.3.5

Ensure that a specialist who is knowledgeable about stomas (such as a stoma nurse or a colorectal surgeon) gives any person who is having surgery (and their family members or carers as appropriate) specific information about the siting, care and management of stomas.

Assessing likelihood of needing surgery

NICE CG 166 Recommendation 1.2.16 (Key priority for implementation)

Assess and document on admission, and then daily, the likelihood of needing surgery for people admitted to hospital with acute severe ulcerative colitis.

Specialist surgical settings and staff

Patient management

Guidelines for the management of inflammatory bowel disease in adults, Section 6.6.2 Indications for surgery

IBD surgery should be undertaken by colorectal surgeons (or their supervised trainees), who are core members of the IBD team in a unit where the operations are performed regularly.

Surgery for ulcerative colitis

Guidelines for the management of inflammatory bowel disease in adults, Section 5.5.3 p20

- IBD surgery should be undertaken by colorectal surgeons in a unit where the operations are performed regularly
- pouch failure and salvage should be managed in a high-volume specialist unit

4.4.3 Current UK practice

Information prior to surgery

In the IBD audits of adult and paediatric services (2011) 73% of sites provide written information for adult patients regarding surgery and 55% of paediatric sites do.

Specialist surgical settings and staff

The IBD audits of adult and paediatric services (2011) reported the following:

- 17% of adult sites and 5% of paediatric sites submit data (including outcomes) about patients with IBD who undergo surgery to a national registry.
- 59% of adult sites hold joint or parallel gastroenterology/colorectal surgery clinics where IBD patients are seen.
- At 74% of adult sites in England and at 53% in Wales both Consultant Gastroenterologists and Colorectal Surgeons regularly attend the IBD Team meetings.
- 83% of adult sites in England and 53% in Wales were sites where surgeons perform ileo-anal pouch surgery on site.
- 42% of paediatric sites hold joint and 29% hold parallel gastroenterology/colorectal surgery clinics where IBD patients are seen.

- 75% of paediatric sites were sites where surgeons perform ileo-anal pouch surgery on site.

The UK audit of adult IBD inpatient care (2012) reports that 39.6% of surgery in England was undertaken laparoscopically for adult patients with ulcerative colitis and 35.6% for patients with Crohn's disease. The UK audit of paediatric IBD inpatient care (2012) states that for paediatric patients 42% of non-elective and 43% of elective surgery for patients with ulcerative colitis and 36% of non-elective and 27% of elective surgery for patients with Crohn's disease was undertaken laparoscopically.

4.5 Treatment

4.5.1 Summary of suggestions

Exclusive enteral nutrition as primary treatment for Crohn's disease

The use of exclusive enteral nutrition to induce disease remission followed by structured food re-introduction diets was suggested as a primary treatment and to help maintain disease remission.

Drug treatment

Appropriate medical management, such as using appropriate therapies and regimens, was highlighted as a way of achieving remission faster and more cost-effectively, aiding adherence and reducing relapses. Assessing the need for dose escalation, optimisation and changes in treatment as well as monitoring the effects of drugs on patients was raised. Stakeholders stated the importance of ensuring that patients with IBD are not on steroids for long periods and managing medication risks.

Rapid referral for relapse

Stakeholders stated that 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. Treatment planning and clear routes back into specialist care are highlighted as patients have reported having no action plan agreed with their medical team to deal with flare-ups and difficulties contacting their specialist team. Delays waiting for appointments are also raised. Rapid access to specialist care when needed is raised in relation to children and young people with IBD specifically.

Co-ordination of care

Stakeholders highlighted the need for improved co-ordination and better communication between primary and secondary care, which could be facilitated by shared access to patient management plans. Managing aspects of care for people with IBD in primary care instead of in secondary care is suggested to take services closer to the patient. The key role of a multidisciplinary team in the safe and effective management of IBD is mentioned.

4.5.2 Selected recommendations from development sources

Table 8 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

| Suggested quality improvement area | Selected source guidance recommendations |
|----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Exclusive enteral nutrition as primary treatment for Crohn's disease | <p>Monotherapy NICE CG152 Recommendation 1.2.2</p> <p>Maintaining remission in Crohn's disease after surgery NICE CG152 Recommendation 1.4.3</p> |
| Drug treatment | <p>Add-on treatment NICE CG152 Recommendations 1.2.7 and 1.2.9</p> <p>Add-on treatment NICE CG152 Recommendations 1.2.10 (KPI) and 1.2.11 (KPI)</p> <p>Infliximab and adalimumab NICE CG152 Recommendations 1.2.12, 1.2.14, 1.2.15 and 1.2.16</p> <p>Maintenance treatment for those who choose this option NICE CG 152 Recommendation 1.3.7 (KPI)</p> <p>Monitoring treatment NICE CG166 Recommendation 1.2.15 (KPI)</p> <p>All extents of disease NICE CG166 Recommendation 1.4.4</p> <p>Dosing regimen for oral aminosalicylates NICE CG 166 Recommendation 1.4.6 (KPI)</p> |
| Rapid referral for relapse | <p>Follow-up during remission for those who choose not to receive maintenance treatment NICE CG 152 Recommendation 1.3.3</p> <p>Patient management (IBD Standard A4) Guidelines for the management of inflammatory bowel disease in adults, p4 bullet point 8</p> |
| Co-ordination of care | <p>Patient information and support NICE CG152 Recommendation 1.1.2 (KPI)</p> <p>Add-on treatment NICE CG152 Recommendation 1.2.11 (KPI)</p> <p>Crohn's disease limited to the distal</p> |

| | |
|--|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | <p>ileum NICE CG152 Recommendation 1.5.2</p> <p>Patient information and support NICE CG166 Recommendation 1.1.1 (KPI)</p> <p>The multidisciplinary team NICE CG166 Recommendation 1.2.10</p> <p>Monitoring treatment NICE CG166 Recommendation 1.2.15 (KPI)</p> <p>Multi-disciplinary care (IBD Standard A3) Guidelines for the management of inflammatory bowel disease in adults p4 bullet point 1</p> <p>Table 2 IBD service standards Guidelines for the management of inflammatory bowel disease in adults p4 Table 2, Standard B</p> |
|--|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Exclusive enteral nutrition as primary treatment for Crohn's disease

Monotherapy

NICE CG152 Recommendation 1.2.2

Consider enteral nutrition as an alternative to a conventional glucocorticosteroid to induce remission for:

- children in whom there is concern about growth or side effects, and
- young people in whom there is concern about growth.

Maintaining remission in Crohn's disease after surgery

NICE CG152 Recommendation 1.4.3

Do not offer budesonide or enteral nutrition to maintain remission after surgery.

Drug treatment

Add-on treatment

NICE CG152 Recommendation 1.2.7

Consider adding azathioprine or mercaptopurine to a conventional glucocorticosteroid or budesonide to induce remission of Crohn's disease if:

- there are two or more inflammatory exacerbations in a 12-month period, or

- the glucocorticosteroid dose cannot be tapered.

NICE CG152 Recommendation 1.2.9

Consider adding methotrexate to a conventional glucocorticosteroid or budesonide to induce remission in people who cannot tolerate azathioprine or mercaptopurine, or in whom TPMT activity is deficient, if:

- there are two or more inflammatory exacerbations in a 12-month period, or
- the glucocorticosteroid dose cannot be tapered.

Add-on treatment

NICE CG152 Recommendation 1.2.10 (Key priority for implementation)

Monitor the effects of azathioprine, mercaptopurine and methotrexate as advised in the current online version of the British national formulary (BNF) or British national formulary for children (BNFC). Monitor for neutropenia in those taking azathioprine or mercaptopurine even if they have normal TPMT activity.

NICE CG152 Recommendation 1.2.11 (Key priority for implementation)

Ensure that there are documented local safety monitoring policies and procedures (including audit) for adults, children and young people receiving treatment that needs monitoring. Nominate a member of staff to act on abnormal results and communicate with GPs and people with Crohn's disease and/or their parents or carers, if appropriate.

Infliximab and adalimumab

NICE CG152 Recommendation 1.2.12

Infliximab and adalimumab, within their licensed indications, are recommended as treatment options for adults with severe active Crohn's disease (see 1.2.17) whose disease has not responded to conventional therapy (including immunosuppressive and/or corticosteroid treatments), or who are intolerant of or have contraindications to conventional therapy. Infliximab or adalimumab should be given as a planned course of treatment until treatment failure (including the need for surgery), or until 12 months after the start of treatment, whichever is shorter. People should then have their disease reassessed (see 1.2.15) to determine whether ongoing treatment is still clinically appropriate.

NICE CG152 Recommendation 1.2.14

Infliximab, within its licensed indication, is recommended as a treatment option for people with active fistulising Crohn's disease whose disease has not responded to conventional therapy (including antibiotics, drainage and immunosuppressive treatments), or who are intolerant of or have contraindications to conventional

therapy. Infliximab should be given as a planned course of treatment until treatment failure (including the need for surgery) or until 12 months after the start of treatment, whichever is shorter. People should then have their disease reassessed (see 1.2.15) to determine whether ongoing treatment is still clinically appropriate.

NICE CG152 Recommendation 1.2.15

Treatment with infliximab or adalimumab (see 1.2.12 and 1.2.14) should only be continued if there is clear evidence of ongoing active disease as determined by clinical symptoms, biological markers and investigation, including endoscopy if necessary. Specialists should discuss the risks and benefits of continued treatment with patients and consider a trial withdrawal from treatment for all patients who are in stable clinical remission. People who continue treatment with infliximab or adalimumab should have their disease reassessed at least every 12 months to determine whether ongoing treatment is still clinically appropriate. People whose disease relapses after treatment is stopped should have the option to start treatment again.

NICE CG152 Recommendation 1.2.16

Infliximab, within its licensed indication, is recommended for the treatment of people aged 6–17 years with severe active Crohn's disease whose disease has not responded to conventional therapy (including corticosteroids, immunomodulators and primary nutrition therapy), or who are intolerant of or have contraindications to conventional therapy. The need to continue treatment should be reviewed at least every 12 months.

Maintenance treatment for those who choose this option

NICE CG 152 Recommendation 1.3.7 (Key priority for implementation)

Do not offer a conventional glucocorticosteroid or budesonide to maintain remission.

Monitoring treatment

NICE CG166 Recommendation 1.2.15 (Key priority for implementation)

Ensure that there are documented local safety monitoring policies and procedures (including audit) for adults, children and young people receiving treatment that needs monitoring (aminosalicylates, tacrolimus, ciclosporin, infliximab, azathioprine and mercaptopurine). Nominate a member of staff to act on abnormal results and communicate with GPs and people with ulcerative colitis (and/or their parents or carers as appropriate).

All extents of disease

NICE CG166 Recommendation 1.4.4

Consider oral azathioprine or oral mercaptopurine to maintain remission:

- after two or more inflammatory exacerbations in 12 months that require treatment with systemic corticosteroids **or**
- if remission is not maintained by aminosalicylates

Dosing regimen for oral aminosalicylates

NICE CG 166 Recommendation 1.4.6 (Key priority for implementation)

Consider a once-daily dosing regimen for oral aminosalicylates when used for maintaining remission. Take into account the person's preferences, and explain that once-daily dosing can be more effective, but may result in more side effects.

Rapid referral for relapse

Follow-up during remission for those who choose not to receive maintenance treatment

NICE CG 152 Recommendation 1.3.3

When people choose not to receive maintenance treatment:

- discuss and agree with them, and/or their parents or carers if appropriate, plans for follow-up, including the frequency of follow-up and who they should see
- ensure they know which symptoms may suggest a relapse and should prompt a consultation with their healthcare professional (most frequently, unintended weight loss, abdominal pain, diarrhoea, general ill-health)
- ensure they know how to access the healthcare system if they experience a relapse
- discuss the importance of not smoking.

Patient management (IBD Standard A4)

Guidelines for the management of inflammatory bowel disease in adults, p4 bullet point 8

Patients experiencing a possible relapse of their IBD should have access to specialist review within a maximum of five working days (Standard A11).

Co-ordination of care

Patient information and support

NICE CG152 Recommendation 1.1.2 (Key priority for implementation)

Discuss treatment options and monitoring with the person with Crohn's disease, and/or their parent or carer if appropriate, and within the multidisciplinary team.

Apply the principles outlined in [Patient experience in adult NHS services](#) (NICE clinical guidance 138).

Add-on treatment

NICE CG152 Recommendation 1.2.11 (Key priority for implementation)

Ensure that there are documented local safety monitoring policies and procedures (including audit) for adults, children and young people receiving treatment that needs monitoring. Nominate a member of staff to act on abnormal results and communicate with GPs and people with Crohn's disease and/or their parents or carers, if appropriate.

The multidisciplinary team

NICE CG166 Recommendation 1.2.10

For people admitted to hospital with acute severe ulcerative colitis:

- ensure that a gastroenterologist and a colorectal surgeon collaborate to provide treatment and management
- ensure that the composition of the multidisciplinary team is appropriate for the age of the person
- seek advice from a paediatrician with expertise in gastroenterology when treating a child or young person
- ensure that the obstetric and gynaecology team is included when treating a pregnant woman.

Multi-disciplinary care (IBD Standard A3)

Guidelines for the management of inflammatory bowel disease in adults p4 bullet point 1

The IBD team should have regular meetings to discuss patients with complex needs.

Table 2 IBD service standards

Guidelines for the management of inflammatory bowel disease in adults p4 Table 2, Standard B

Local delivery of care

4.5.3 Current UK practice

Exclusive enteral nutrition as primary treatment for Crohn's disease

In the UK audit of adult IBD inpatient care (2012) 21% of sites said that exclusive liquid enteral nutrition therapy was prescribed when dietary treatment was initiated

and 71% said that supplemental liquid enteral nutrition therapy was prescribed. In the UK audit of paediatric IBD inpatient care (2012) 75% of sites said that exclusive liquid enteral nutrition therapy was prescribed when dietary treatment was initiated and 31% said that supplemental liquid enteral nutrition therapy was prescribed.

Drug treatment

Results of the UK audits of adult and paediatric IBD inpatient care (2012) demonstrate that 93% of adult patients and 88% of paediatric patients who were receiving steroids were placed onto a steroid reduction programme on discharge. 21% of adult patients and 16% of paediatric patients had been taking steroids (at any time) for longer than 3 months continuously prior to the admission.

The national IBD audit of biological therapies adult report (2013)¹² reports that 43% of adults with Crohn's disease waited longer than 2 weeks to begin treatment on Infliximab, with 33% of this delay attributed to waiting for the next available clinic appointment. 98% of Crohn's disease initial Infliximab treatments are given over 2 hours, in line with prescribing guidelines. 23% of Crohn's disease patients are given a lower dose induction regime (80/40mg) for Adalimumab. This is associated with a greater frequency of dose escalation in the long term. 57% of patients were recorded as having been appropriately prescribed anti-TNF α treatment, when compared against NICE TA187 criterion 1.1.

The national IBD audit of biological therapies paediatric report (2013)¹³ reports that 39% of Crohn's disease patients waited more than 2 weeks to begin treatment on Infliximab, with 39% of this delay attributed to waiting for the next available clinic appointment. The majority of Crohn's disease patients (91%) are receiving concomitant therapy at initial treatment. Of these, 90% are receiving an immunosuppressant at initial Infliximab treatment. Only 11% of patients were recorded as having been appropriately prescribed anti-TNF α treatment, when compared against NICE TA187 criterion 1.5.

Rapid referral for relapse

Key findings from the IBD audit of adult services (2011) showed that rapid access to specialist services was good with 94% of sites reviewed offering expedited review, in addition to 92% of sites reporting that they see patients within 7 days of referral. 79% of sites confirmed that written information on who to contact in the event of a relapse was available for patients with IBD. Reported information from the IBD audit of paediatric services (2011) confirms that 91% of patients with IBD have written information on who to contact in case of a relapse and a further 91% of patients can

¹² Royal College of Physicians (2013) National clinical audit of biological therapies: UK Inflammatory Bowel Disease (IBD) audit - Adult national report

¹³ Royal College of Physicians (2013) National clinical audit of biological therapies: UK Inflammatory Bowel Disease (IBD) audit - Paediatric national report

expect to be seen for specialist review within a 7 day period and 65% within 5 days. 98% of adult sites and 83% of paediatric sites said there was access to endoscopy within 72 hrs of admission for patients admitted with relapse.

However in the UK IBD primary care questionnaire (2012) 59% of GPs indicated they are unable to get their patients seen in a secondary care setting within 7 days of relapse, despite many hospitals insisting that rapid access exists and is available. GPs are also concerned that they are not clear about who is available and who they can contact. Only 6.1% of GPs are very confident at dealing with acute exacerbations of IBD, with 9.1% saying they are not confident, 31.5% saying slightly confident and 53.3% somewhat confident.

Co-ordination of care

In the IBD audits of adult and paediatric services (2011) only 34% of adult sites and 26% of paediatric sites said there is a defined protocol in place between the IBD Service and GPs for shared outpatient management. 75% of adult sites and 83% of paediatric sites report that there are regular timetabled IBD Team meetings held to discuss IBD patients.

Results from the UK IBD primary care questionnaire (2012) show that 76% of patients who had been admitted to hospital were being seen in secondary care, and had been for an outpatient appointment in hospital during the 12 months prior to the indicated admission. This suggests that the majority of patients are being seen in secondary rather than primary care. GPs indicated that the primary care team, or a combination of primary and secondary care, monitored established immunosuppressive therapy in 78% of cases.

4.6 Patient education, information and support

4.6.1 Summary of suggestions

Dietetic support

Stakeholders highlighted that dietitians are essential in the nutritional management of aspects of IBD, such as functional gastrointestinal symptoms (e.g. abdominal pain, bloating, flatulence and diarrhoea). They also felt that dieticians can provide dietary advice and monitor functional symptoms in IBD, as well as iron and calcium status. The need for patients to be provided with information and education regarding dietary considerations and therapy was raised as a way of enabling self-management of the condition and reducing the risk of nutritional complications. The fact that few IBD services have the recommended number of dieticians dedicated to IBD and that only a minority of in-patients are seen by a dietitian was raised.

Stakeholders stated that access to dietetic services as part of the IBD team should be available across the boundaries of primary and secondary care.

Psychological support

Stakeholders felt that psychological support for patients with IBD, in particular support from psychologists with an interest in IBD, is at inadequate levels in both adult and paediatric services. The importance of psychological and quality of life assessment due to the psychosocial impact of IBD was raised.

Information and support

Stakeholders highlighted that age and culturally-appropriate patient information of a high quality should be provided for patients with IBD, as well as information in other formats, such as audio or video, for people who have difficulty reading. Suggestions for the types of information to provide included how to manage the condition, information about discharge medicines (including side effects), danger signals to be aware of after going home, how to access support and a written care plan.

Stakeholders stated the importance of educational opportunities for patients and their carers in enabling patients to take control of the management of their illness, to support decisions about medical or surgical treatment and to understand the importance of following their treatment to prevent relapses and worsening of their condition. Issues were raised around patients not being involved in decisions about their care.

IBD nurse

Stakeholders highlighted the key role of the IBD nurse in the provision of information, education and support for patients, for example, through helplines, clinics and email contact. The issue of inadequate IBD nurse staffing

levels, and suspension of their specialist services when cover is required, was raised. The need for counselling by a paediatric gastroenterology clinical nurse specialist for children with IBD (and their carers) before starting treatment with an immunosuppressing agent or biologic was highlighted.

4.6.2 Selected recommendations from development sources

Table 9 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 9 to help inform the Committee’s discussion.

Table 9 Specific areas for quality improvement

| Suggested quality improvement area | Selected source guidance recommendations |
|-------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Dietetic support | Management of Crohn’s disease Guidelines for the management of inflammatory bowel disease in adults Section 6.0 IBD Service Standards p21 |
| Psychological support | Information when considering surgery NICE CG166 Recommendation 1.3.4 Information after surgery NICE CG166 Recommendation 1.3.6 (KPI) Psychological aspects Guidelines for the management of inflammatory bowel disease in adults Section 7.9, IBD service standard p29 |
| Information and support | Patient information and support NICE CG152 Recommendations 1.1.1 to 1.1.6 (KPIs 1.1.1, 1.1.2, 1.1.5, 1.1.6) Maintaining remission in Crohn’s disease NICE CG152 Recommendation 1.3.1 (KPI) Follow-up during remission for those who choose not to receive maintenance treatment NICE CG 152 Recommendation 1.3.3 Patient information and support NICE CG166 Recommendations 1.1.1 to 1.1.3 (KPI 1.1.1) |
| IBD nurse | Information when considering surgery NICE CG166 Recommendations 1.3.1 (KPI), 1.3.4, 1.3.5 Information after surgery NICE CG166 Recommendation 1.3.6 (KPI) |

Dietetic support

Management of Crohn's disease

Guidelines for the management of inflammatory bowel disease in adults Section 6.0 IBD Service Standards p21

- Access to a dietician and nutritional support should be available to all patients with IBD (Standard A5).

Psychological support

Information when considering surgery

NICE CG166 Recommendation 1.3.4

Ensure that a specialist (such as a colorectal surgeon, a gastroenterologist, an inflammatory bowel disease nurse specialist or a stoma nurse) gives any person who is considering surgery (and their family members or carers as appropriate) information about:

- diet
- sensitive topics such as sexual function
- effects on lifestyle
- psychological wellbeing
- the type of surgery, the possibility of needing a stoma and stoma care.

Information after surgery

NICE CG166 Recommendation 1.3.6 (Key priority for implementation)

After surgery, ensure that a specialist who is knowledgeable about stomas (such as a stoma nurse or a colorectal surgeon) gives the person (and their family members or carers as appropriate) information about managing the effects on bowel function. This should be specific to the type of surgery performed (ileostomy or ileoanal pouch) and could include the following:

- strategies to deal with the impact on their physical, psychological and social wellbeing
- where to go for help if symptoms occur
- sources of support and advice.

Psychological aspects

Guidelines for the management of inflammatory bowel disease in adults Section 7.9 p29, IBD Service Standard

Psychological support should be available to patients with IBD (IBD Standard A2).

Information and support

Patient information and support

NICE CG152 Recommendation 1.1.1(Key priority for implementation)

Ensure that information and advice about Crohn's disease:

- is age appropriate
- is of the appropriate cognitive and literacy level, and
- meets the cultural and linguistic needs of the local community.

NICE CG152 Recommendation 1.1.2 (Key priority for implementation)

Discuss treatment options and monitoring with the person with Crohn's disease, and/or their parent or carer if appropriate, and within the multidisciplinary team. Apply the principles outlined in [Patient experience in adult NHS services](#) (NICE clinical guidance 138).

NICE CG152 Recommendation 1.1.3

Discuss the possible nature, frequency and severity of side effects of drug treatment with people with Crohn's disease, and/or their parents or carers if appropriate.

NICE CG152 Recommendation 1.1.4

Give all people with Crohn's disease, and/or their parents or carers if appropriate, information, advice and support in line with published NICE guidance on:

- smoking cessation
- patient experience
- medicines adherence
- fertility.

NICE CG152 Recommendation 1.1.5 (Key priority for implementation)

Give people with Crohn's disease, and/or their parents or carers if appropriate, additional information on the following when appropriate:

- possible delay of growth and puberty in children and young people
- diet and nutrition
- fertility and sexual relationships
- prognosis
- side effects of their treatment
- cancer risk
- surgery
- care of young people in transition between paediatric and adult services
- contact details for support groups.

NICE CG152 Recommendation 1.1.6 (Key priority for implementation)

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.

Maintaining remission in Crohn's disease

NICE CG152 Recommendation 1.3.1 (Key priority for implementation)

Discuss with people with Crohn's disease, and/or their parents or carers if appropriate, options for managing their disease when they are in remission, including both no treatment and treatment. The discussion should include the risk of inflammatory exacerbations (with and without drug treatment) and the potential side effects of drug treatment. Record the person's views in their notes.

Follow-up during remission for those who choose not to receive maintenance treatment

NICE CG 152 Recommendation 1.3.3

When people choose not to receive maintenance treatment:

- discuss and agree with them, and/or their parents or carers if appropriate, plans for follow-up, including the frequency of follow-up and who they should see
- ensure they know which symptoms may suggest a relapse and should prompt a consultation with their healthcare professional (most frequently, unintended weight loss, abdominal pain, diarrhoea, general ill-health)

- ensure they know how to access the healthcare system if they experience a relapse
- discuss the importance of not smoking.

Patient information and support

NICE CG166 Recommendation 1.1.1 (Key priority for implementation)

Discuss the disease and associated symptoms, treatment options and monitoring:

- with the person with ulcerative colitis, and their family members or carers as appropriate **and**
- within the multidisciplinary team (the composition of which should be appropriate for the age of the person) at every opportunity.

Apply the principles in [Patient experience in adult NHS services](#) (NICE clinical guideline 138).

NICE CG166 Recommendation 1.1.2

Discuss the possible nature, frequency and severity of side effects of drug treatment for ulcerative colitis with the person, and their family members or carers as appropriate. Refer to [Medicines adherence](#) (NICE clinical guideline 76).

NICE CG166 Recommendation 1.1.3

Give the person, and their family members or carers as appropriate, information about their risk of developing colorectal cancer and about colonoscopic surveillance, in line with the NICE clinical guidelines on:

- [Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas](#) (NICE clinical guideline 118)
- [Referral for suspected cancer](#) (NICE clinical guideline 27).

IBD Nurse

Information when considering surgery

NICE CG166 Recommendation 1.3.1 (Key priority for implementation)

For people with ulcerative colitis who are considering surgery, ensure that a specialist (such as a gastroenterologist or a nurse specialist) gives the person (and their family members or carers as appropriate) information about all available treatment options, and discusses this with them. Information should include the benefits and risks of the different treatments and the potential consequences of no treatment.

NICE CG 166 Recommendation 1.3.4

Ensure that a specialist (such as a colorectal surgeon, a gastroenterologist, an inflammatory bowel disease nurse specialist or a stoma nurse) gives any person who is considering surgery (and their family members or carers as appropriate) information about:

- diet
- sensitive topics such as sexual function
- effects on lifestyle
- psychological wellbeing
- the type of surgery, the possibility of needing a stoma and stoma care.

NICE CG 166 Recommendation 1.3.5

Ensure that a specialist who is knowledgeable about stomas (such as a stoma nurse or a colorectal surgeon) gives any person who is having surgery (and their family members or carers as appropriate) specific information about the siting, care and management of stomas.

Information after surgery

NICE CG166 Recommendation 1.3.6 (Key priority for implementation)

After surgery, ensure that a specialist who is knowledgeable about stomas (such as a stoma nurse or a colorectal surgeon) gives the person (and their family members or carers as appropriate) information about managing the effects on bowel function. This should be specific to the type of surgery performed (ileostomy or ileoanal pouch) and could include the following:

- strategies to deal with the impact on their physical, psychological and social wellbeing
- where to go for help if symptoms occur
- sources of support and advice.

4.6.3 Current UK practice

Dietetic support

The UK audits of adult and paediatric IBD inpatient care (2012) report that 38% of non-elective adult patients with Crohn's disease and 81% of non-elective paediatric patients with Crohn's disease were seen by a dietician during their admission. This

correlates with the UK IBD audit inpatient experience questionnaire responses report (2012)¹⁴, where only 38% of adults reported a visit from a dietician during their inpatient stay, compared to 71% of paediatric patients.

The IBD audits of adult and paediatric services (2011) reported that 60% of adult sites and 96% of paediatric sites said they had at least 0.5WTE dieticians allocated to gastroenterology. 92% of paediatric sites and 68% of adult sites have defined access to a nutrition support team with an interest in IBD.

Psychological support

According to the IBD audits of adult and paediatric services (2011) defined access to psychologists and counsellors with an interest in IBD is available in 67% and 13% of paediatric sites and 24% and 9% of adult sites respectively.

Information and support

The UK IBD audit inpatient experience report (2012) highlights that in response to questions on information and advice about discharge medicines only 6% of patients reported not receiving an explanation of the purpose of the treatments but 32% recalled no instruction about side effects to watch out for. 11% of respondents reported receiving no written information about discharge medicines. 30% of patients reported that no staff member had told them about danger signals to watch for after going home and 17% felt that they were not given enough information about how to manage their condition after discharge. 40% of respondents reported that they did not receive a copy of the letters sent between the hospital and family doctor (GP). 13% of IBD patients felt that they were not involved in decisions about discharge.

The UK IBD audits of adult and paediatric services (2011) reported that:

- 95% of adult sites said patients have access to an IBD Specialist by telephone, 10% have access at a drop in clinic and 55% by email.
- 99% of adult sites said patients are provided with written information about IBD and 83% said that this information includes details of treatment options so that patients can make an informed choice about their treatment.
- 35% of adult sites provided information in languages other than English, 92% have specific information for newly diagnosed patients and 33% provide a written care plan.
- 100% of paediatric sites said patients have access to an IBD Specialist by telephone and 65% by email.

¹⁴ Royal College of Physicians (2012) National report of the results of the UK IBD audit 3rd round inpatient experience questionnaire responses.

- 100% of paediatric sites said patients are provided with written information about IBD and 82% said that this information includes details of treatment options so that patients can make an informed choice about their treatment.
- 39% of paediatric sites provided information in languages other than English, 96% have specific information for newly diagnosed patients and 43% provide a written care plan.

IBD nurse

The UK IBD audits of adult and paediatric services (2011) reported that 21% of adult sites said that there are at least 1.5 WTE IBD Nurse Specialists in the IBD Team and 83% of paediatric sites said there are at least 0.5 WTE paediatric gastro/IBD Nurse Specialists in the IBD Team.

According to the UK audit of adult IBD inpatient care (2012) 42% of adult non-elective patients with ulcerative colitis and 35% with Crohn's disease were seen by an IBD nurse specialist during admission. The audit of paediatric inpatient care (2012) reports that 71% of paediatric non-elective patients with ulcerative colitis and 72% with Crohn's disease were seen by an IBD nurse specialist during admission. Results from the inpatient experience report (2012) state that only 60% of adults and 76% of children indicated that they had a visit from a specialist nurse during their inpatient stay.

4.7 Additional area

4.7.1 Summary of suggestions

The improvement area below was suggested as part of the stakeholder engagement exercise, however it was felt to be covered by an existing quality standard ([Nutrition support in adults](#). NICE quality standard 24(2012)). It has been included here to allow for further discussion by the Committee regarding statement development.

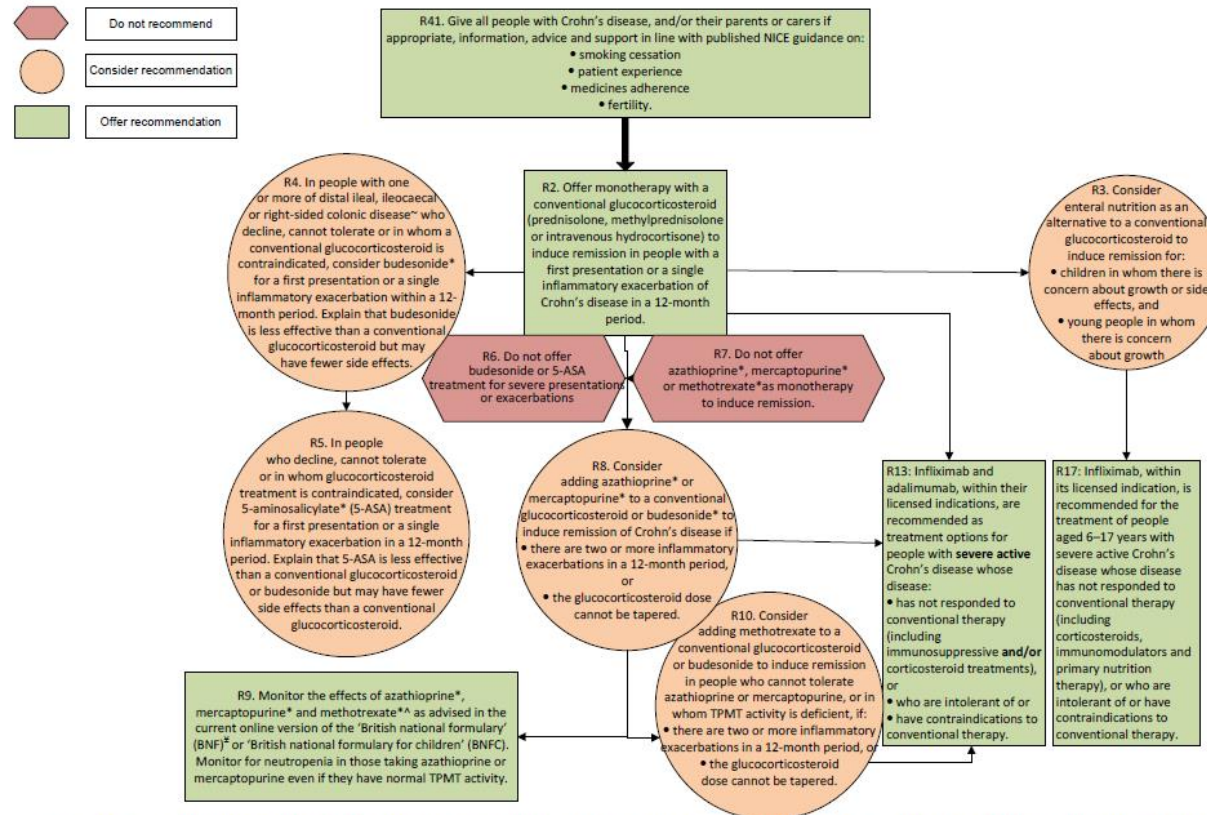
There will be an opportunity for the QSAC to discuss this area at the end of the session on 24 February 2014.

Screening admitted patients for malnutrition

Stakeholders suggested that IBD patients admitted to hospital should undergo nutritional screening as malnutrition is common in IBD patients.

Appendix 1: Inducing remission in Crohn's disease

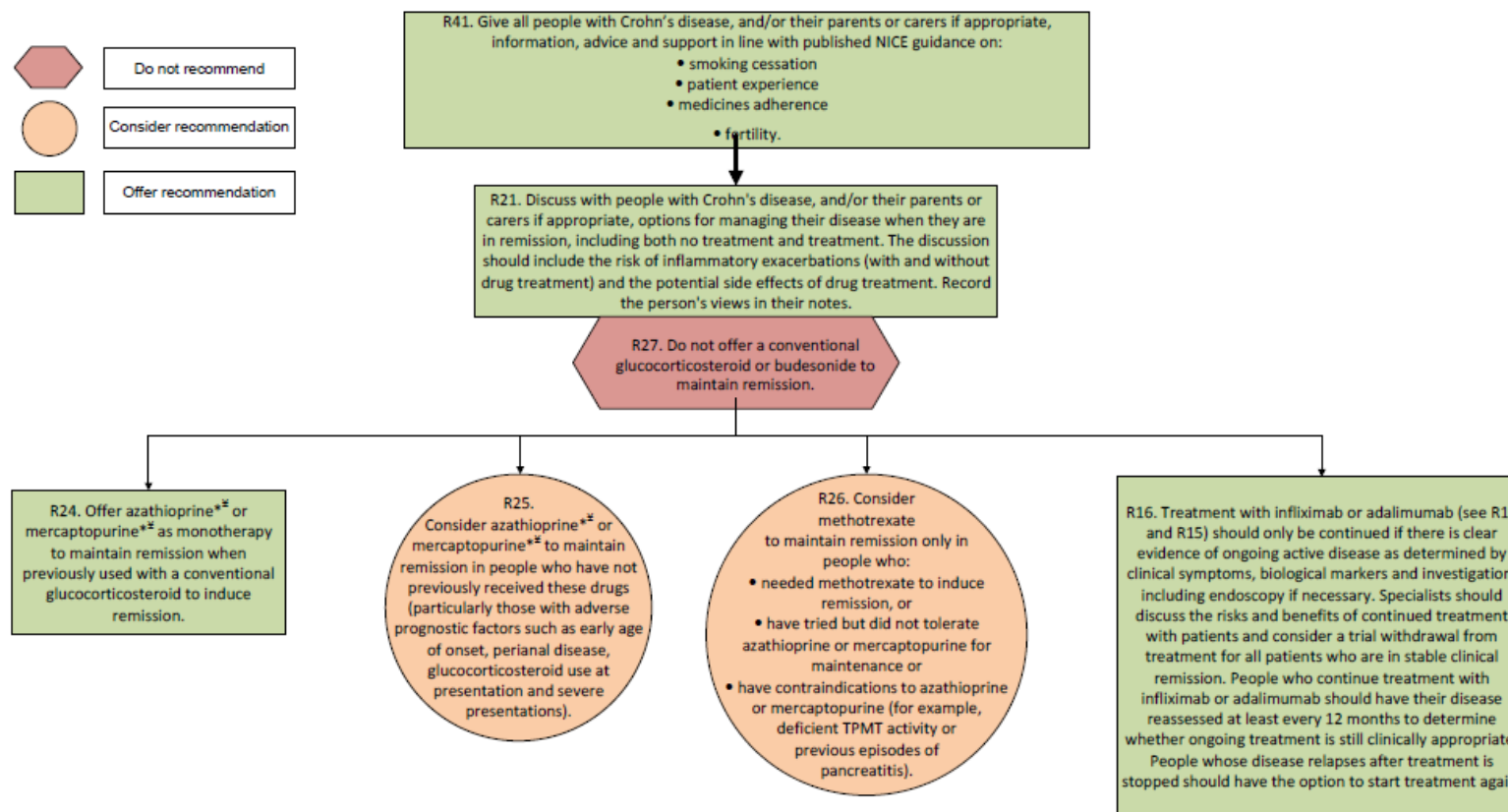
Taken from full clinical guideline 152



*See recommendation 31 and 32 for when to consider surgery early in the course of the disease for people whose disease is limited to the distal ileum. **Although use is common in UK clinical practice, at the time of publication (October 2012) azathioprine, mercaptopurine, methotrexate, mesalazine, olsalazine and balsalazide did not have UK marketing authorisation for inducing remission in Crohn's disease and budesonide did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing medicines – guidance for doctors for further information. † Follow BNF/BNFC cautions on prescribing methotrexate. ‡ Advice on monitoring of immunosuppressives can be found in the BNF/BNFC. The gastroenterology chapter and other relevant sections should be consulted.

Appendix 2: Maintaining remission in Crohn's disease

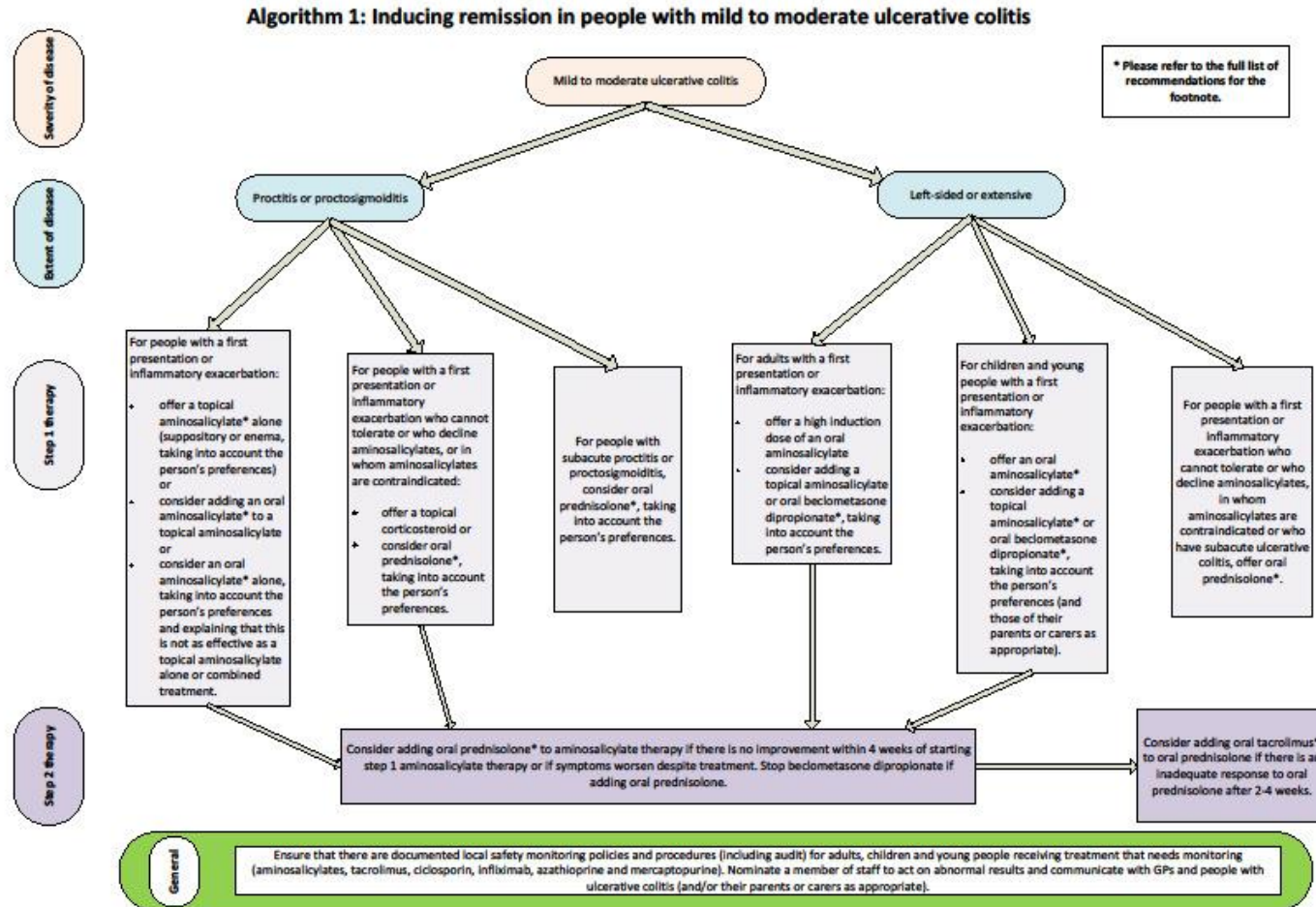
Taken from full clinical guideline 152



* Although use is common in UK clinical practice, at the time of publication (October 2012), azathioprine, mercaptopurine and methotrexate did not have UK marketing authorisation for maintaining remission in Crohn's disease. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing medicines – guidance for doctors for further information. [†]Follow BNF/BNFC cautions on prescribing methotrexate. [‡]Advice on monitoring of immunosuppressives can be found in the BNF/BNFC. The gastroenterology chapter and other relevant sections should be consulted.

Appendix 3: Inducing remission in people with mild to moderate ulcerative colitis

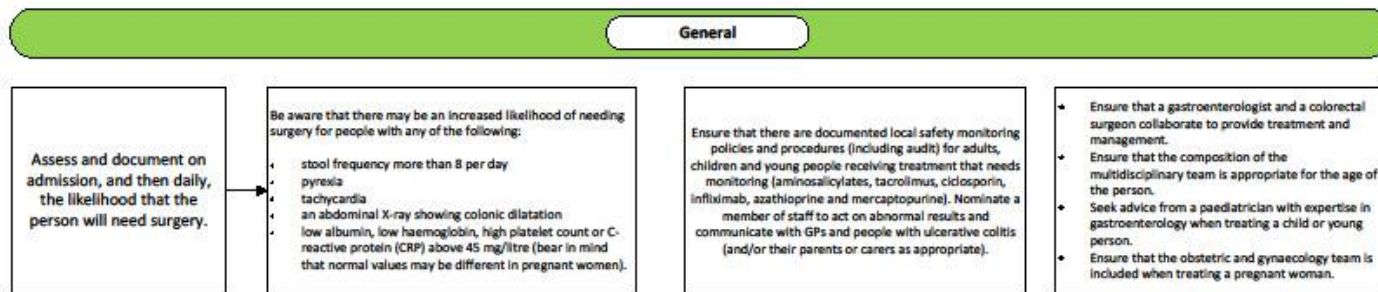
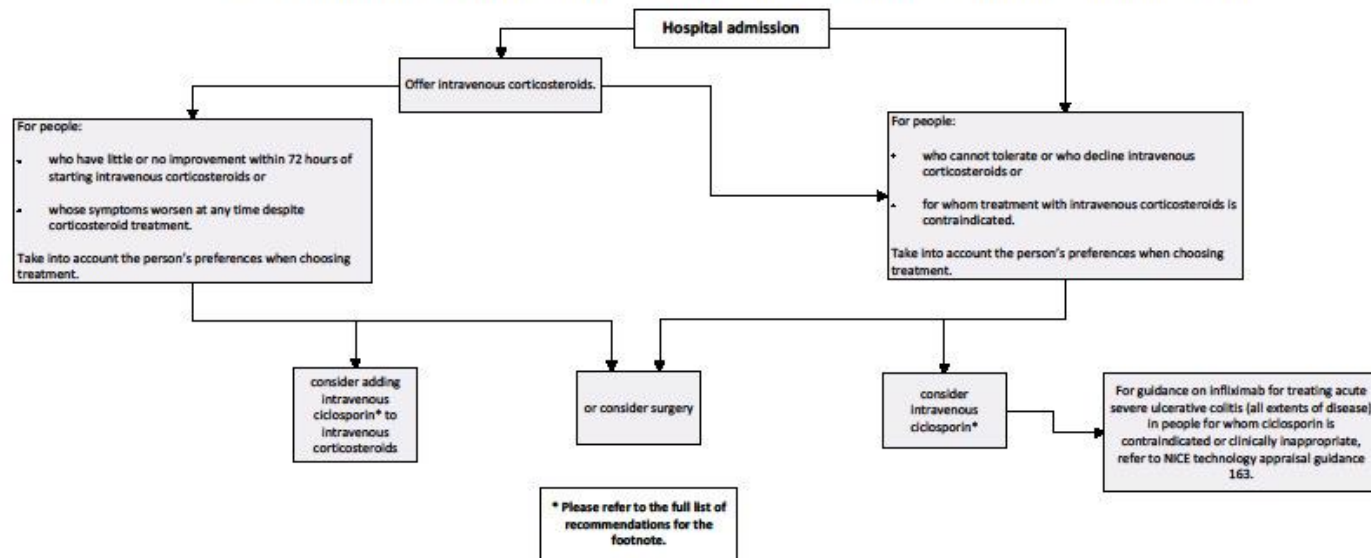
Taken from full clinical guideline 166



Appendix 4: Inducing remission in people with acute severe ulcerative colitis (all extents of disease)

Taken from full clinical guideline 166

Algorithm 2: Inducing remission in people with acute severe ulcerative colitis (all extents of disease)



Appendix 5: Key priorities for implementation (CG152)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

- Ensure that information and advice about Crohn's disease:
 - is age appropriate
 - is of the appropriate cognitive and literacy level, and
 - meets the cultural and linguistic needs of the local community.

- Discuss treatment options and monitoring with the person with Crohn's disease, and/or their parent or carer if appropriate, and within the multidisciplinary team. Apply the principles outlined in [Patient experience in adult NHS services](#) (NICE clinical guidance 138).

- Give people with Crohn's disease, and/or their parents or carers if appropriate, additional information on the following when appropriate:
 - possible delay of growth and puberty in children
 - diet and nutrition
 - fertility and sexual relationships
 - prognosis
 - side effects of their treatment
 - cancer risk
 - surgery
 - care of young people in transition between paediatric and adult services
 - contact details for support groups.

- 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.

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- Assess thiopurine methyltransferase (TPMT) activity before offering azathioprine or mercaptopurine^[1]. Do not offer azathioprine or mercaptopurine if TPMT activity is deficient (very low or absent). Consider azathioprine or mercaptopurine at a lower dose if TPMT activity is below normal but not deficient (according to local laboratory reference values).
- Monitor the effects of azathioprine, mercaptopurine and methotrexate^{[2], [3]} as advised in the current online version of the British national formulary (BNF)^[4] or British national formulary for children (BNFC). Monitor for neutropenia in those taking azathioprine or mercaptopurine even if they have normal TPMT activity.
- Ensure that there are documented local safety monitoring policies and procedures (including audit) for adults, children and young people receiving treatment that needs monitoring. Nominate a member of staff to act on abnormal results and communicate with GPs and people with Crohn's disease and/or their parents or carers, if appropriate.
- Discuss with people with Crohn's disease, and/or their parents or carers if appropriate, options for managing their disease when they are in remission, including both no treatment and treatment. The discussion should include the risk of inflammatory exacerbations (with and without drug treatment) and the potential side effects of drug treatment. Record the person's views in their notes.
- Do not offer a conventional glucocorticosteroid or budesonide to maintain remission.

^[1] Although use is common in UK clinical practice, at the time of publication (October 2012) azathioprine and mercaptopurine did not have UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the GMC's Good practice in prescribing medicines – guidance for doctors for further information.

^[2] Although use is common in UK clinical practice, at the time of publication (October 2012) azathioprine, mercaptopurine and methotrexate did not have UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the GMC's Good practice in prescribing medicines – guidance for doctors for further information.

^[3] Follow BNF/BNFC cautions on prescribing methotrexate.

^[4] Advice on monitoring of immunosuppressives can be found in the current online version of BNF/BNFC. The gastroenterology chapter and other relevant sections should be consulted.

Appendix 6: Key priorities for implementation (CG166)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Patient information and support

- Discuss the disease and associated symptoms, treatment options and monitoring:
 - with the person with ulcerative colitis, and their family members or carers as appropriate and
 - within the multidisciplinary team (the composition of which should be appropriate for the age of the person) at every opportunity.

Apply the principles in [Patient experience in adult NHS services](#) (NICE clinical guideline 138).

Inducing remission: step 1 therapy for mild to moderate

ulcerative colitis

- To induce remission in people with a mild to moderate first presentation or inflammatory exacerbation of proctitis or proctosigmoiditis:
 - offer a topical aminosalicylate^[1] alone (suppository or enema, taking into account the person's preferences) or
 - consider adding an oral aminosalicylate^[2] to a topical aminosalicylate or
 - consider an oral aminosalicylate^[2] alone, taking into account the person's preferences and explaining that this is not as effective as a topical aminosalicylate alone or combined treatment.
- To induce remission in adults with a mild to moderate first presentation or inflammatory exacerbation of left-sided or extensive ulcerative colitis:
 - offer a high induction dose of an oral aminosalicylate
 - consider adding a topical aminosalicylate or oral beclometasone dipropionate^[3], taking into account the person's preferences.

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- To induce remission in children and young people with a mild to moderate first presentation or inflammatory exacerbation of left-sided or extensive ulcerative colitis:
 - offer an oral aminosalicylate^{[2],[4]}
 - consider adding a topical aminosalicylate^[1] or oral beclometasone dipropionate^[5], taking into account the person's preferences (and those of their parents or carers as appropriate).

Inducing remission: step 2 therapy for acute severe ulcerative colitis

- Consider adding intravenous ciclosporin^[6] to intravenous corticosteroids or consider surgery for people:
 - who have little or no improvement within 72 hours of starting intravenous corticosteroids or
 - whose symptoms worsen at any time despite corticosteroid treatment.

Take into account the person's preferences when choosing treatment.

Monitoring treatment

- Ensure that there are documented local safety monitoring policies and procedures (including audit) for adults, children and young people receiving treatment that needs monitoring (aminosalicylates, tacrolimus, ciclosporin, infliximab, azathioprine and mercaptopurine). Nominate a member of staff to act on abnormal results and communicate with GPs and people with ulcerative colitis (and/or their parents or carers as appropriate).

Assessing likelihood of needing surgery

- Assess and document on admission, and then daily, the likelihood of needing surgery for people admitted to hospital with acute severe ulcerative colitis.

Information about treatment options for people who are considering surgery

- For people with ulcerative colitis who are considering surgery, ensure that a specialist (such as a gastroenterologist or a nurse specialist) gives the person (and their family members or carers as appropriate) information about all available treatment options, and discusses this with them. Information should include the benefits and risks of the different treatments and the potential consequences of no treatment.
- After surgery, ensure that a specialist who is knowledgeable about stomas (such as a stoma nurse or a colorectal surgeon) gives the person (and their family members or carers as appropriate) information about managing the effects on bowel function. This should be specific to the type of surgery performed (ileostomy or ileoanal pouch) and could include the following:
 - strategies to deal with the impact on their physical, psychological and social wellbeing
 - where to go for help if symptoms occur
 - sources of support and advice.

Maintaining remission

- Consider a once-daily dosing regimen for oral aminosalicylates^[7] when used for maintaining remission. Take into account the person's preferences, and explain that once-daily dosing can be more effective, but may result in more side effects.

^[1] At the time of publication (June 2013), some topical aminosalicylates did not have a UK marketing authorisation for this indication in children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

^[2] At the time of publication (June 2013), some oral aminosalicylates did not have a UK marketing authorisation for this indication in children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

^[3] At the time of publication (June 2013), beclometasone dipropionate only has a UK marketing authorisation 'as add-on therapy to 5-ASA containing drugs in patients who are non-responders to 5-ASA therapy in active phase'. For use outside these licensed indications, the prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

^[4] Dosing requirements for children should be calculated by body weight, as described in the BNF.

^[5] At the time of publication (June 2013), beclometasone dipropionate did not have a UK marketing authorisation for this indication in children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

^[6] At the time of publication (June 2013), ciclosporin did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

^[7] At the time of publication (June 2013), not all oral aminosalicylates had a UK marketing authorisation for once-daily dosing. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing and managing medicines and devices for further information.

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