

# Inflammatory bowel disease

Quality standard

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This standard is based on CG166 and CG152.

This standard should be read in conjunction with QS15, QS20, QS24, QS43, QS54 and QS114.

## Introduction

This quality standard covers the diagnosis and management of inflammatory bowel disease (Crohn's disease and ulcerative colitis) in adults, children and young people. For more information see the [topic overview](#).

### *Why this quality standard is needed*

The 2 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. Symptoms of active disease or relapse of ulcerative colitis include bloody diarrhoea, an urgent need to defecate and abdominal pain. People with inflammatory bowel disease can go for long periods with few or no symptoms (this is known as remission), but these can be followed by a period of active disease when symptoms flare up (this is sometimes called a relapse or an exacerbation).

In the UK, it is estimated that at least 115,000 people have Crohn's disease ([Crohn's disease NICE guideline CG152, 2012](#)) and around 146,000 have a diagnosis of ulcerative colitis ([Ulcerative colitis NICE guideline CG166, 2013](#)). Inflammatory bowel disease can be painful, disrupt normal activities and reduce quality of life, particularly during periods of active disease. It can affect social and psychological wellbeing and increase the person's risk of developing other conditions, such as colorectal cancer, osteoporosis and anaemia. It can also impair growth and pubertal development in children and young people.

The aim when treating inflammatory bowel disease is either to heal the inflammation and so reduce symptoms during a flare-up ('inducing remission') or to prevent flare-ups happening in the future ('maintaining remission'). There are various drugs that can help with both of these aims. Choice of drug treatment may include aminosalicylates, corticosteroids and biological drugs for ulcerative

colitis, and glucocorticosteroids, aminosalicylates, antibiotics, immunosuppressives and tumour necrosis factor (TNF) alfa inhibitors for Crohn's disease. Surgery may also be an option for some people. Details of treatment options for people with inflammatory bowel disease can be found in [Crohn's disease](#) (NICE guideline CG152), [ulcerative colitis](#) (NICE guideline CG166) and [infliximab, adalimumab and golimumab for treating moderately to severely active ulcerative colitis after the failure of conventional therapy](#) (NICE technology appraisal guidance 329).

The quality standard is expected to contribute to improvements in the following outcomes:

- attendance at school
- sickness absence from work
- unplanned hospital admissions for inflammatory bowel disease
- length of hospital stay after surgery for inflammatory bowel disease
- readmissions after surgery for inflammatory bowel disease
- people with long-term conditions feeling supported to manage their condition
- patient experience of services.

### *How this quality standard supports delivery of outcome frameworks*

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- [NHS Outcomes Framework 2015–16](#)
- [Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, Parts 1A, 1B and 2.](#)

Tables 1 and 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 2015–16**

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p><b>Overarching indicator</b></p> <p>1b Life expectancy at 75 (i) Males (ii) Females</p> <p><b>Improvement area</b></p> <p>1.4 Under 75 mortality rate from cancer*</p>
2 Enhancing quality of life for people with long-term conditions	<p><b>Overarching indicator</b></p> <p>2 Health-related quality of life for people with long-term conditions</p> <p><b>Improvement areas</b></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*</p>
3 Helping people to recover from episodes of ill health or following injury	<p><b>Overarching indicator</b></p> <p>3b Emergency readmissions within 30 days of discharge from hospital*</p>

<p>4 Ensuring that people have a positive experience of care</p>	<p><b>Overarching indicators</b></p> <p>4a Patient experience of primary care (i) GP services</p> <p>4b Patient experience of hospital care</p> <p><b>Improvement areas</b></p> <p><b>Improving people's experience of outpatient care</b></p> <p>4.1 Patient experience of outpatient services</p> <p><b>Improving hospitals' responsiveness to personal needs</b></p> <p>4.2 Responsiveness to in-patients' personal needs</p> <p><b>Improving children and young people's experience of healthcare</b></p> <p>4.8 Children and young people's experience of inpatient services</p> <p><b>Improving people's experience of integrated care</b></p> <p>4.9 People's experience of integrated care</p>
<p><b>Alignment across the health and social care system</b></p> <p>* Indicator shared with Public Health Outcomes Framework</p>	

**Table 2 Public health outcomes framework for England, 2013–2016**

Domain	Objectives and indicators
<p>1 Improving the wider determinants of health</p>	<p><b>Objective</b></p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities</p> <p><b>Indicators</b></p> <p>1.3 Pupil absence</p> <p>1.8i Employment for those with long-term health conditions</p> <p>1.9 Sickness absence rate</p>



<p>2 Health improvement</p>	<p><b>Objective</b></p> <p>People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p><b>Indicators</b></p> <p>2.23 Self-reported wellbeing</p>
<p>4 Healthcare public health and preventing premature mortality</p>	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities</p> <p><b>Indicator</b></p> <p>4.5 Under 75 mortality rate from cancer</p> <p>4.11 Emergency readmissions within 30 days of discharge from hospital</p>

### *Patient experience and safety issues*

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to inflammatory bowel disease.

NICE has developed guidance and an associated quality standard on patient experience in adult NHS services (see the NICE pathway on [patient experience in adult NHS services](#)), which should be considered alongside this quality standard. It specifies that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. It also covers the provision of information to patients and service users. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development source(s) for quality standards that impact on patient experience and are specific to the topic are considered during quality statement development.

### *Coordinated services*

The quality standard for inflammatory bowel disease specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole inflammatory bowel disease care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with inflammatory bowel disease.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality inflammatory bowel disease service are listed in [related NICE quality standards](#).

## Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating people with inflammatory bowel disease should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source(s) on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

## Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with inflammatory bowel disease. If appropriate, healthcare professionals should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

## List of quality statements

Statement 1. People with suspected inflammatory bowel disease have a specialist assessment within 4 weeks of referral.

Statement 2. Services provide age-appropriate support from a multidisciplinary team for people with inflammatory bowel disease, and their family members or carers.

Statement 3. People having surgery for inflammatory bowel disease have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

Statement 4. People receiving drug treatment for inflammatory bowel disease are monitored for adverse effects.

## Quality statement 1: Specialist assessment

### *Quality statement*

People with suspected inflammatory bowel disease have a specialist assessment within 4 weeks of referral.

### *Rationale*

A confirmed diagnosis of inflammatory bowel disease is always made in an age-appropriate specialist setting using a combination of haematological, endoscopic, histological and imaging-based investigations. A delay in assessment and diagnosis can be associated with adverse consequences, such as clinical complications and a negative effect on the person's quality of life. Some people with suspected inflammatory bowel disease who have severe symptoms will need an urgent specialist assessment, the urgency of which will depend on clinical need and might include an emergency admission, but no one should wait more than 4 weeks from referral for a specialist assessment.

### *Quality measures*

#### **Structure**

Evidence of local referral pathways to ensure that people with suspected inflammatory bowel disease have a specialist assessment within 4 weeks of referral.

**Data source:** Local data collection. Data on referral pathways for urgent referrals are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), question OC1.2, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), question OC2.1.

#### **Process**

Proportion of people with suspected inflammatory bowel disease who have a specialist assessment within 4 weeks of referral.

Numerator – the number in the denominator who have a specialist assessment within 4 weeks of referral.

Denominator – the number of people with suspected inflammatory bowel disease who are referred for specialist assessment.

**Data source:** Local data collection. Data on the time it takes for urgent referrals to be seen are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), question OC1.3, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), questions OC2.4 and 2.6.

## Outcome

Patient experience of the referral process.

**Data source:** Local data collection.

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (district general hospitals) ensure that local referral pathways are in place so that people with suspected inflammatory bowel disease are referred quickly and efficiently, and have a specialist assessment within 4 weeks of referral.

**Healthcare professionals** ensure that they follow agreed local referral pathways so that people with suspected inflammatory bowel disease are referred quickly and efficiently, and have a specialist assessment within 4 weeks of referral.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services that make use of agreed local referral pathways so that people with suspected inflammatory bowel disease are referred quickly and efficiently, and have a specialist assessment within 4 weeks of referral. This can be achieved through enhanced monitoring of contracts and establishing regular and timely auditing procedures.

### *What the quality statement means for patients, service users and carers*

**People with suspected inflammatory bowel disease** are seen by a specialist in hospital for an assessment within 4 weeks of being referred by their GP. This means that a diagnosis can be made without delay and treatment options can be discussed. The specialist assessment might involve having blood tests or endoscopy (using a camera to provide images of the inside of the body). Inflammatory bowel disease includes Crohn's disease and ulcerative colitis. Sometimes it is not possible to tell whether a person has Crohn's disease or ulcerative colitis, and they may be described as having 'inflammatory bowel disease unclassified' (IBDU).

## Source guidance

- British Society of Gastroenterology (2011) [Guidelines for the management of inflammatory bowel disease in adults](#), section 3.3 'Diagnosis and investigation' and 'IBD Service Standards for diagnosis and investigation (IBD standard A)'.
  - The timeframe of 4 weeks is based on consensus of expert opinion.

## Definitions of terms used in this quality statement

### Suspected inflammatory bowel disease

People with any of the following lower gastrointestinal symptoms that have been present for at least 6 weeks should be suspected of having inflammatory bowel disease:

- abdominal pain or discomfort
- bloating
- change in bowel habit (such as diarrhoea with or without rectal bleeding).

Faecal biomarkers, such as faecal calprotectin, alongside clinical assessment may be useful in primary care to distinguish between suspected inflammatory bowel disease and non-inflammatory bowel disease, such as irritable bowel syndrome. [Adapted from [Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel](#) NICE diagnostics guidance 11, section 3.1, and [IBD Standards](#), standard A4]. The Quality Standard Advisory Committee noted that, in some people with severe symptoms, inflammatory bowel disease might be suspected before the symptoms have been present for 6 weeks, and these people need earlier referral (before 6 weeks).

### Specialist assessment

People with suspected inflammatory bowel disease should be referred for specialist assessment using local referral pathways by a GP directly to a defined specialist (consultant gastroenterologist or consultant paediatric gastroenterologist) or to an age-appropriate inflammatory bowel disease service. Specialist assessment enables consideration of a possible diagnosis of inflammatory bowel disease using a range of investigations. These include clinical evaluation and a combination of biochemical, endoscopic, radiological and histological investigations to confirm a diagnosis. [Expert opinion and [British Society of Gastroenterology guidelines](#), section 3.3]

## **Within 4 weeks of referral**

The timeframe of 4 weeks is based on expert consensus and is intended to be a safety net to ensure that no one waits longer than 4 weeks for specialist assessment. However, it is recognised that some people with suspected inflammatory bowel disease who have severe symptoms will need an urgent specialist assessment. In such cases 'within 4 weeks' is subject to clinical judgement and a considerably shorter timeframe may be necessary, for example within 2 weeks. Therefore an effective local referral pathway should ensure that people with suspected inflammatory bowel disease are seen within 4 weeks of referral, or more rapidly if clinically necessary. Services that already see patients earlier than 4 weeks from referral should maintain this speed of referral and assessment. [Expert opinion and [IBD Standards](#), standard A4]

## ***Equality and diversity considerations***

The symptoms of inflammatory bowel disease may have a different impact on people of different gender, sexuality, culture and age. Referral processes and assessments need to be sensitive to individual anxieties and take into account any additional needs, such as the availability of doctors of the same sex, and any language barriers.

## Quality statement 2: Multidisciplinary team support

### *Quality statement*

Services provide age-appropriate support from a multidisciplinary team for people with inflammatory bowel disease, and their family members or carers.

### *Rationale*

Inflammatory bowel disease can have diverse effects on a person. In addition to its physical impact, there can be emotional, psychological and social consequences. A multidisciplinary team has a wide range of expertise that can help address these issues, and it is important that services for people with inflammatory bowel disease provide this support.

### *Quality measures*

#### **Structure**

Evidence that services provide age-appropriate support from a multidisciplinary team for people with inflammatory bowel disease, and their family members or carers.

**Data source:** Local data collection. Data on patient support and the inflammatory bowel disease team are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), sections 2 and 3, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), sections 2 and 3.

#### **Process**

a) Proportion of people with inflammatory bowel disease where there is a documented discussion about their needs, and the needs of their family members or carers (if appropriate), for age-appropriate support from a multidisciplinary team.

Numerator – the number in the denominator where there is a documented discussion about their needs, and the needs of their family members or carers (if appropriate), for age-appropriate support from a multidisciplinary team.

Denominator – the number of people with inflammatory bowel disease.

**Data source:** Local data collection. Contained within the Royal College of Physicians' [National](#)



clinical audit of inpatient care for adults with ulcerative colitis.

b) Proportion of people with inflammatory bowel disease whose needs, and the needs of their family members or carers (if appropriate), for age-appropriate support from a multidisciplinary team are met.

Numerator – the number in the denominator whose needs, and the needs of their family members or carers (if appropriate), for age-appropriate support from a multidisciplinary team are met.

Denominator – the number of people with inflammatory bowel disease whose needs for age-appropriate support from a multidisciplinary team are recorded.

*Data source:* Local data collection.

## Outcome

a) Satisfaction of people with inflammatory bowel disease with the support provided.

*Data source:* Local data collection. The [Experience of inpatients with ulcerative colitis throughout the UK audit](#) asks various questions about patient experience of support in hospital.

b) Satisfaction of family members or carers of people with inflammatory bowel disease with the support provided.

*Data source:* Local data collection.

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (district general hospitals) ensure that systems are in place so that people with inflammatory bowel disease, and their family members or carers, have age-appropriate support from a multidisciplinary team.

**Healthcare professionals** work within a multidisciplinary team to provide age-appropriate support to people with inflammatory bowel disease, and their family members or carers.

**Commissioners** (clinical commissioning groups) ensure that they commission services in which people with inflammatory bowel disease, and their family members or carers, have age-appropriate

support from a multidisciplinary team.

## *What the quality statement means for patients, service users and carers*

People with inflammatory bowel disease, and their family members or carers, have support from a care team made up of a range of different professionals (including nurses, doctors, dietitians and pharmacists). The type of support they get should depend on the person's age (for example, whether they are an adult or a child), and should help to deal with any concerns about the condition and its treatment.

## *Source guidance*

- British Society of Gastroenterology (2011) [Guidelines for the management of inflammatory bowel disease in adults](#), section 2.0 'Service delivery: IBD Service Standards (service delivery), The IBD Team' (IBD Service Standards A1 and A2)
- [Crohn's disease](#) (2012) NICE guideline CG152, recommendation 1.1.6 (key priority for implementation)
- [Ulcerative colitis](#) (2013) NICE guideline CG166, recommendations 1.1.1 (key priority for implementation) and 1.2.10

## *Definitions of terms used in this quality statement*

### **Age-appropriate support**

Age-appropriate support should be broad-based and offered by those who are best placed at the time to meet the needs of people with inflammatory bowel disease and their family members or carers. A person's support needs will vary depending on age. For example, a child or young person's concerns might be more focused on body image, transition between services and attending school and higher education, whereas an adult might be more concerned with employment and sexual issues. Other issues for which people may need support include concerns about the disease and its treatment, nutrition and diet, and other aspects of living with a chronic illness. Support could include signposting to reliable and accurate information on a broad range of topics or having access to a dedicated telephone or email service where people can raise concerns or questions. [Adapted from [Crohn's disease NICE guideline CG152 and IBD Standards](#), standard A11]

### **Multidisciplinary team**

An inflammatory bowel disease multidisciplinary team should comprise gastroenterologists,

colorectal surgeons and clinical nurse specialists with particular expertise and specialist interest in inflammatory bowel disease, a dietitian allocated to gastroenterology, and a pharmacist, pathologist and radiologist with special interest in gastroenterology. The team should have access to essential supporting services with an interest in inflammatory bowel disease, including a psychologist or counsellor, rheumatologist, ophthalmologist, dermatologist, obstetrician, nutrition support team, paediatric gastroenterology clinical network and general practice. There should be a named clinical lead for the inflammatory bowel disease team. [Adapted from [IBD Standards](#), standards A1 and A2]

## Quality statement 3: Surgery

### *Quality statement*

People having surgery for inflammatory bowel disease have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

### *Rationale*

Better patient outcomes are more likely if surgery for inflammatory bowel disease is undertaken by a colorectal surgeon with expertise and experience in inflammatory bowel disease surgery, with the support of an experienced clinical team. Such expertise is most likely to be in a unit where such surgery is performed regularly. The expertise and experience of the clinical team will enable the best judgement of when to undertake surgery, and should ensure the quality of clinical care before, during and after surgery.

### *Quality measures*

#### Structure

Evidence of local arrangements to ensure that people having surgery for inflammatory bowel disease have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

**Data source:** Local data collection. Data on surgery for inflammatory bowel disease are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), section 3, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), section 3.

#### Process

Proportion of surgical procedures for inflammatory bowel disease undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

Numerator – the number in the denominator undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

Denominator – the number of surgical procedures for inflammatory bowel disease.

**Data source:** Local data collection and [Hospital episode statistics](#) from The Health and Social Care

Information Centre.

## Outcome

Complications after surgery.

**Data source:** Local data collection. Data on surgical complications are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#) and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), section 3, and the [National clinical audit of inpatient care for adults with ulcerative colitis](#) and the [National clinical audit of inpatient care for young people with ulcerative colitis](#), section 4.2.

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (district general hospitals and specialist tertiary centres) ensure that surgery for inflammatory bowel disease is undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

**Healthcare professionals** undertake inflammatory bowel disease surgery if they are colorectal surgeons with expertise and experience in such surgery, or refer people to a colorectal surgeon with relevant expertise and experience who is a core member of the inflammatory bowel disease multidisciplinary team.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services from providers who can demonstrate that surgery for inflammatory bowel disease is undertaken by colorectal surgeons who are core members of inflammatory bowel disease multidisciplinary teams.

### *What the quality statement means for patients, service users and carers*

People who have surgery for inflammatory bowel disease have their operation carried out by a specialist surgeon called a colorectal surgeon who is a member of the inflammatory bowel disease care team. This will make it more likely that the operation is a success and ensure good care. Patients should always be involved in the decision to have surgery after a discussion of the benefits and risks.

## *Source guidance*

- British Society of Gastroenterology (2011) [Guidelines for the management of inflammatory bowel disease in adults](#), section 5.5 'Recommendations for surgery in ulcerative colitis' and section 6.6.2 'Recommendations for surgery in Crohn's disease' (IBD Service Standards A7)

## *Definitions of terms used in this quality statement*

### **Surgery for inflammatory bowel disease**

The types of operation performed for inflammatory bowel disease include colectomy, ileo-anal pouch procedure, ileostomy and intestinal resection. [Adapted from [Crohn's disease](#) NICE guideline CG152, [Ulcerative colitis](#) NICE guideline CG166 and [British Society of Gastroenterology guidelines](#)]

### **Colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team**

The surgeon should have expertise and experience in undertaking surgery for inflammatory bowel disease and be able to make informed decisions about the need for surgery and the timing of surgery. Their predominant workload should involve inflammatory bowel disease and they should be a core member of the inflammatory bowel disease multidisciplinary team. Skilled and experienced surgeons, supported by an experienced clinical team, are most likely to be in units where such surgery is performed regularly.

When emergency procedures have to be performed, these may need to be done by a surgeon with the appropriate skills and experience who is available to perform the surgery. Children and young people should have their operations performed by surgeons with expertise in operating on children and young people with inflammatory bowel disease.

[Expert opinion and [IBD Standards](#), standard A12]

## *Equality and diversity considerations*

People from different cultures who need certain surgical procedures for inflammatory bowel disease, such as stoma operations, may need additional support if such procedures are not considered acceptable in their community.

## Quality statement 4: Monitoring drug treatment

### *Quality statement*

People receiving drug treatment for inflammatory bowel disease are monitored for adverse effects.

### *Rationale*

People with inflammatory bowel disease may experience different responses to drug treatment, including adverse effects. How a person responds to drug treatment therefore needs to be monitored using local safety policies and procedures, and treatment adjusted to ensure the best quality-of-life outcomes and patient safety.

### *Quality measures*

#### **Structure**

Evidence of documented local safety policies and procedures to monitor for adverse effects in people receiving drug treatment for inflammatory bowel disease.

**Data source:** Local data collection. Data on local protocols and monitoring arrangements for immunosuppressives are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), section 3, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), section 3.

#### **Process**

Proportion of people receiving drug treatment for inflammatory bowel disease who are monitored for adverse effects.

Numerator – the number in the denominator for whom there is documented evidence that there is monitoring for adverse effects of drug treatment according to local safety policies and procedures.

Denominator – the number of people receiving drug treatment for inflammatory bowel disease.

**Data source:** Local data collection. Data on local protocols and monitoring arrangements for immunosuppressives are available in the [National audit of inflammatory bowel disease \(IBD\) service provision](#), section 3, and the [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#), section 3. Data on treatment follow-up, acute reactions and adverse events are

available in the results tables of the [National clinical audit of biological therapies, Adult report and Paediatric report](#).

## Outcome

The number of adverse events reported because of drug treatment for inflammatory bowel disease.

**Data source:** Local data collection. Data on adverse events are available in the results tables of the [National clinical audit of biological therapies, Adult report and Paediatric report](#).

### *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (general practices and district general hospitals) ensure that they have documented local safety policies and procedures that are used for monitoring for adverse effects in people receiving drug treatment for inflammatory bowel disease and for acting on abnormal results.

**Healthcare professionals** ensure that they monitor for adverse effects in people receiving drug treatment for inflammatory bowel disease, using documented local safety policies and procedures, and they act on abnormal results.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services in which there is monitoring for adverse effects in people receiving drug treatment for inflammatory bowel disease, using documented local safety policies and procedures, and abnormal results are acted on.

### *What the quality statement means for patients, service users and carers*

**People taking medication for inflammatory bowel disease** have regular check-ups for any side effects, and healthcare professionals take action if there are any concerns. This will lower the chances of the person having problems caused by the medication. People should be helped by their care team to understand treatment options and monitoring, including benefits, risks and possible consequences.



## Source guidance

- British Society of Gastroenterology (2011) [Guidelines for the management of inflammatory bowel disease in adults](#), section 5.0 'Management of ulcerative colitis' and section 6.0 'Management of Crohn's disease'
- [Crohn's disease](#) (2012) NICE guideline CG152, recommendations 1.2.10 and 1.2.11 (key priorities for implementation)
- [Ulcerative colitis](#) (2013) NICE guideline CG166, recommendation 1.2.15 (key priority for implementation)

## Definitions of terms used in this quality statement

### Drug treatment for inflammatory bowel disease

A number of drugs are used to treat inflammatory bowel disease, depending on the type and severity of the disease, observed side effects, contraindications and patient preference. Drugs used include aminosalicylates, corticosteroids, biological treatments and immunosuppressives. Full details of treatment options for people with inflammatory bowel disease, including drug treatment, can be found in [NICE guideline CG152](#) and [NICE guideline CG166](#). [Adapted from [Crohn's disease](#) NICE guideline CG152 and [Ulcerative colitis](#) NICE guideline CG166]

### Monitoring for adverse effects

Treatment of inflammatory bowel disease aims to induce remission and control symptoms. Monitoring for adverse effects should identify side effects and potential adverse outcomes from long-term use. Treatments that can cause adverse outcomes include thiopurines, methotrexate, aminosalicylates, immunosuppressives and corticosteroids. [Adapted from [Crohn's disease](#) NICE guideline CG152 and [Ulcerative colitis](#) NICE guideline CG166]

Full details of side effects, contraindications and monitoring (including blood tests, procedures and clinical review) that should be carried out for specific drugs are detailed in the current online version of the [British national formulary](#) or [British national formulary for children](#).

### Local safety policies and procedures

There should be monitoring for adverse effects in people having drug treatment for inflammatory bowel disease using local safety policies and procedures. These should include:

- shared care arrangements between primary and secondary care and clearly defined responsibilities for healthcare professionals in primary and secondary care
- clear referral pathways
- locally agreed monitoring guidelines
- clear access routes to urgent care
- a nominated member or members of the multidisciplinary team to act on abnormal results and reports of side effects and communicate with relevant healthcare professionals and people with inflammatory bowel disease (and/or their family members or carers, as appropriate).  
[Adapted from Crohn's disease NICE guideline CG152 and Ulcerative colitis NICE guideline CG166, and expert opinion]

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [what makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

### *Levels of achievement*

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

### *Using other national guidance and policy documents*

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).

### *Information for commissioners*

NICE has produced [support for commissioning](#) that considers the commissioning implications and potential resource impact of this quality standard. This is available on the NICE website.

## *Information for the public*

NICE has produced [information for the public](#) about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care services.

## Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between healthcare professionals and people with inflammatory bowel disease, and their families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with inflammatory bowel disease and their families or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

## Development sources

Further explanation of the methodology used can be found in the quality standards [process guide](#) on the NICE website.

## Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [Ulcerative colitis](#) (2013) NICE guideline CG166
- [Crohn's disease](#) (2012) NICE guideline CG152
- [Guidelines for the management of inflammatory bowel disease in adults](#) British Society of Gastroenterology (2011)

## Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- Department of Health (2006) [Transition: getting it right for young people](#)

## Definitions and data sources for the quality measures

- The Health and Social Care Information Centre (2015) [Hospital episode statistics](#)
- BMJ Group and the Royal Pharmaceutical Society of Great Britain (2014) [British national formulary](#)
- BMJ Group and the Royal Pharmaceutical Society of Great Britain (2014) [British national formulary for children](#)
- Royal College of Physicians (2014) [National audit of inflammatory bowel disease \(IBD\) service provision](#)
- Royal College of Physicians (2014) [National audit of paediatric inflammatory bowel disease \(IBD\) service provision](#)

- Royal College of Physicians (2014) [National clinical audit of biological therapies, Adult report](#)
- Royal College of Physicians (2014) [National clinical audit of biological therapies, Paediatric report](#)
- Royal College of Physicians (2014) [Experience of inpatients with ulcerative colitis throughout the UK audit](#)
- Royal College of Physicians (2014) [National clinical audit of inpatient care for adults with ulcerative colitis](#)
- Royal College of Physicians (2014) [National clinical audit of inpatient care for young people with ulcerative colitis](#)
- Inflammatory bowel disease standards (2013) [Standards for the healthcare of people who have inflammatory bowel disease](#)
- NICE diagnostics guidance 11 (2013) [Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel](#)

## Related NICE quality standards

### *Published*

- [Faecal incontinence](#) (2014) NICE quality standard 54
- [Smoking cessation](#) (2013) NICE quality standard 43
- [Nutrition support in adults](#) (2012) NICE quality standard 24
- [Colorectal cancer](#) (2012) NICE quality standard 20
- [Patient experience in adult NHS services](#) (2012) NICE quality standard 15

### *Future quality standards*

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Medicines optimisation (covering medicines adherence and safe prescribing)
- Nutrition in hospital, including young people
- Osteoporosis
- Referral for suspected cancer
- Transition from children's to adults' services

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.



## Quality Standards Advisory Committee and NICE project team

### *Quality Standards Advisory Committee*

This quality standard has been developed by Quality Standards Advisory Committee 4. Membership of this committee is as follows:

**Miss Alison Allam**

Lay member

**Dr Harry Allen**

Consultant Old Age Psychiatrist, Manchester Mental Health and Social Care Trust

**Mrs Moyra Amess (from November 2014)**

Associate Director, Assurance and Accreditation, CHKS

**Mrs Claire Beynon (until June 2014)**

Head of Threshold Management and Individual Funding Requests, NHS South West Commissioning Support Unit

**Dr Jo Bibby**

Director of Strategy, The Health Foundation

**Mrs Jane Bradshaw**

Lead Nurse Specialist in Neurology, Norfolk Community Health and Care

**Dr Allison Duggal**

Consultant in Public Health, Public Health England

**Mr Tim Fielding**

Consultant in Public Health, North Lincolnshire Council

**Mrs Frances Garraghan**

Lead Pharmacist for Women's Health, Central Manchester Foundation Trust

**Mrs Zoe Goodacre**

Network Manager, South Wales Critical Care Network

**Mr Malcolm Griffiths**

Consultant Obstetrician and Gynaecologist, Luton & Dunstable University Hospital NHS Foundation Trust

**Dr Jane Hanson (until October 2014)**

Head of Cancer National Specialist Advisory Group Core Team, Cancer National Specialist Advisory Group, NHS Wales

**Ms Nicola Hobbs**

Assistant Director of Quality and Contracting, Northamptonshire County Council

**Mr Roger Hughes**

Lay member

**Mr John Jolly**

Chief Executive Officer, Blenheim Community Drug Project, London

**Dr Damien Longson (Chair)**

Consultant Liaison Psychiatrist, Manchester Mental Health and Social Care Trust

**Dr Rubin Minhas**

GP Principal, Oakfield Health Centre, Kent

**Mrs Julie Rigby**

Quality Improvement Programme Lead, Strategic Clinical Networks, NHS England

**Mr Alaster Rutherford**

Primary Care Pharmacist, NHS Bath and North East Somerset

**Mr Michael Varrow**

Information and Intelligence Business Partner, Essex County Council

**Mr John Walker**

Head of Operations, Greater Manchester West Mental Health NHS Foundation Trust

**Mr David Weaver (from November 2014)**

Head of Quality and Safety, North Kent Clinical Commissioning Group

The following specialist members joined the committee to develop this quality standard:

**Dr Nicholas Croft**

Reader and Honorary Consultant in Paediatric Gastroenterology, Queen Mary University of London & Barts Health NHS Trust

**Mr Peter Dryden** (from April 2014 until October 2014)

Children's Inflammatory Bowel Disease Nurse Specialist, The Great North Children's Hospital, Newcastle

**Mr Omar Faiz**

Consultant Colorectal Surgeon, NHS St Mark's Hospital

**Miss Valda Forbes** (until April 2014)

Inflammatory Bowel Disease Nurse Specialist, The Children's Hospital Sheffield

**Professor Alan Lobo**

Consultant Physician and Gastroenterologist and Honorary Professor of Gastroenterology, Sheffield Teaching Hospitals NHS Foundation Trust and University of Sheffield

**Professor John Mayberry**

Consultant Physician and Professor of Gastroenterology, University Hospitals of Leicester NHS Trust

**Dr John O'Malley** (from April 2014)

Medical Director and General Practitioner, Mastercall Healthcare, Manchester

**Mrs Kerry Robinson** (from April 2014)

Inflammatory Bowel Disease Nurse Specialist, Sheffield Teaching Hospitals Foundation Trust

**Mr Nigel Westwood**

Lay member

**Professor Kevin Whelan**

Professor of Dietetics, King's College London

## ***NICE project team***

**Dylan Jones**

Associate Director

**Shirley Crawshaw**

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**Rachel Neary-Jones**

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**Tony Smith**

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**Stacy Wilkinson**

Lead Technical Analyst

**Anthony Gildea**

Project Manager

**Nicola Cunliffe**

Coordinator

## Update information

### Minor changes since publication

December 2016: Data source updated for statement 2.

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard has been incorporated into the NICE pathways on [Crohn's disease](#) and [ulcerative colitis](#).

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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## *Endorsing organisation*

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## *Supporting organisations*

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Association of Coloproctology of Great Britain and Ireland](#)

- [British Dietetic Association](#)
- [British Society of Gastroenterology](#)
- [Crohn's and Colitis UK](#)
- [Royal College of General Practitioners](#)
- [Royal College of Pathologists](#)
- [Royal College of Physicians](#)