



# Inflammatory bowel disease

Quality standard

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This standard is based on NG130 and NG129.

This standard should be read in conjunction with QS15, QS20, QS24, QS43, QS54, QS149, QS140, QS124 and QS120.

## 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## 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 different audiences

**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.

**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 \(BSG\). BSG consensus guidelines on the management of inflammatory bowel disease in adults \(2019\)](#), section 3.1: Ulcerative colitis – diagnosis and section 4.1: Crohn's disease – diagnosis, classification and assessment
- The timeframe of 4 weeks is based on expert consensus and [IBD UK's IBD standards](#), section 2: pre-diagnosis, statement 2.2: timeframe for referral

## 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 [NICE's diagnostic guidance on faecal calprotectin diagnostic tests for inflammatory diseases of](#)

[the bowel](#), section 3.1, and [IBD UK's IBD standards](#), statement 2.1]

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 [BSG consensus guidelines on the management of inflammatory bowel disease in adults](#), sections 3.1 and 4.1]

## 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 UK's IBD standards](#), statements 2.1 and 2.2]

## 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## 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 IBD inpatient experience 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 different audiences

**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.

**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 \(BSG\). BSG consensus guidelines on the management of inflammatory bowel disease in adults \(2019\), section 6.1: IBD service and the multidisciplinary team and good practice recommendation 27](#)
- [Crohn's disease: management. NICE guideline NG129 \(2019\), recommendation 1.1.6](#)
- [Ulcerative colitis: management. NICE guideline NG130 \(2019\), recommendations 1.1.1 and 1.2.15](#)

## 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 [NICE's guideline on Crohn's disease](#) and [IBD UK's IBD standards](#), statement 7.1]

### Multidisciplinary team

An inflammatory bowel disease (IBD) multidisciplinary team should comprise a gastroenterologist, colorectal surgeon, IBD specialist nurse, dietitian allocated to gastroenterology, pharmacist, histopathologist and radiologist, all with expertise in IBD. The team should have access to advice for decisions about specific patients from a stoma nurse, paediatric gastroenterologist, hepatologist, oral medicine, nutrition support team, psychologist, primary care physician, ophthalmologist, rheumatologist, dermatologist, obstetrician and social worker. There should be a designated coordinator for the IBD team. [Adapted from [BSG consensus guidelines on the management of inflammatory bowel disease in adults](#), section 6.1 and good practice recommendation 27]

# 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## 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 [NHS Digital Hospital episode statistics](#).

## 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 different audiences

**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.

**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 \(BSG\). BSG consensus guidelines on the management of inflammatory bowel disease in adults \(2019\), section 6.1: IBD service and the multidisciplinary team and good practice recommendation 27](#)
- [IBD UK. IBD standards \(2019\), section 5: surgery, statement 5.2: appropriate specialist expertise](#)

## 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 [NICE's guidelines on Crohn's disease and ulcerative colitis](#), and the [BSG consensus guidelines on the management of inflammatory bowel disease in adults](#)]

### 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 UK's IBD standards](#), statement 5.1]

## 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## 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](#).

## 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](#).

## What the quality statement means for different audiences

**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.

**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 \(BSG\). BSG consensus guidelines on the management of inflammatory bowel disease in adults \(2019\)](#), good practice recommendation 33
- [Crohn's disease: management. NICE guideline NG129 \(2019\)](#), recommendations 1.2.10 and 1.2.11
- [Ulcerative colitis: management. NICE guideline NG130 \(2019\)](#), recommendation 1.2.21

## 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's guidelines on Crohn's disease and ulcerative colitis](#). [Adapted from [NICE's guidelines on Crohn's disease and ulcerative colitis](#)]

### 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 [NICE's guidelines on Crohn's disease](#) and [ulcerative colitis](#)]

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 [BNF](#) or [BNF 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 [NICE's guidelines on Crohn's disease](#) and [ulcerative colitis](#), and expert opinion]

# Update information

## Minor changes since publication

**May 2020:** Changes have been made to align this quality standard with the updated British Society of Gastroenterology (BSG) consensus guidelines on the management of inflammatory bowel disease in adults and [IBD UK's inflammatory bowel disease standards](#). Definitions, references and source guidance sections have been updated.

**May 2019:** Changes have been made to align this quality standard with the updated [NICE guidelines on Crohn's disease and ulcerative colitis](#). References and source guidance sections have been updated.

**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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standards advisory committees](#) for details about our standing committees. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource

impact work for the source guidance. Organisations are encouraged to use the resource impact products for the source guidance to help estimate local costs:

- [resource impact statement for NICE's guideline on ulcerative colitis](#)
- [resource impact statement for NICE's guideline on Crohn's disease.](#)

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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.

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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 \(RCGP\)](#)
- [Royal College of Pathologists](#)
- [Royal College of Physicians \(RCP\)](#)