

Inflammatory bowel disease

NICE quality standard

Draft for consultation

April 2014

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 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. Symptoms of active disease or relapse of ulcerative colitis include bloody diarrhoea, an urgent need to defaecate 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 an exacerbation).

In the UK, the estimated number of people with Crohn's disease is at least 115,000 and the number of people with a diagnosis of ulcerative colitis is around 146,000¹. 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

¹ [Crohn's disease](#). NICE clinical guideline 152 (2012) and [Ulcerative colitis](#). NICE clinical guideline 166 (2013)

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 and, in some cases, surgery may also be an option.

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

- attendance at school
- work absenteeism
- 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 2014–15](#)
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, [Part 1 and Part 1A](#).

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 2014–15](#)

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p>Overarching indicator</p> <p>1b Life expectancy at 75 (i) Males (ii) Females</p> <p>Improvement area</p> <p>1.4 Under 75 mortality rate from cancer*</p>
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*</p>
4 Ensuring that people have a positive experience of care	<p>Overarching indicators</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 people's experience of outpatient care</p> <p>4.1 Patient experience of outpatient services</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</p>
Alignment across the health and social care system	
* Indicator shared with Public Health Outcomes Framework (PHOF)	

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

Domain	Objectives and indicators
1 Improving the wider determinants of health	<p>Objective</p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities</p> <p>Indicators</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>

2 Health improvement	<p>Objective People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p>Indicators 2.19 Cancer diagnosed at stage 1 and 2 2.23 Self-reported wellbeing</p>
4 Healthcare public health and preventing premature mortality	<p>Objective Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities</p> <p>Indicator 4.5 Under 75 mortality rate from cancer</p>

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 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.

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 are referred for specialist assessment and investigation using agreed local referral pathways.

[Statement 2](#). People with inflammatory bowel disease, and their family members or carers (as appropriate), are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

[Statement 3](#). People with inflammatory bowel disease who need surgery have it undertaken by a colorectal surgeon in a unit where the operations are performed regularly.

[Statement 4](#). People with inflammatory bowel disease who are receiving drug treatment have the response to treatment monitored and are offered other treatment options if needed.

Developmental quality statement

[Statement 5](#). Adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered (and in whom cancer is not suspected), and children with suspected inflammatory bowel disease who have been referred for specialist assessment, are offered faecal calprotectin testing.

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

Questions about the individual quality statements

Question 3 For draft quality statement 2: At the Quality Standards Advisory Committee meeting, the committee discussed the importance of support for people with inflammatory bowel disease (for example, from dietitians and specialist nurses). This statement includes the concept of individualised care and support. Have we captured the important element of patient support in this draft statement and its definitions?

Question 4 For draft quality statement 5: This is a 'developmental' quality standard statement relating to an emerging diagnostic technology. As a developmental statement it may be expected that it will be implemented over a longer timescale than the other statements in this quality standard because changes to patterns of service delivery may need to be put in place. Do you agree that the statement:

- represents an emergent area of practice that is only currently being carried out by a minority of providers and
- needs specific, significant changes to be put in place and
- has the potential to be widely adopted and therefore drive improvement in outcomes?

Quality statement 1: Referral for specialist assessment

Quality statement

People with suspected inflammatory bowel disease are referred for specialist assessment and investigation using agreed local referral pathways.

Rationale

A confirmed diagnosis of inflammatory bowel disease is always made in a specialist (hospital) setting using a combination of haematological, endoscopic, histological and imaging-based investigations. A delay in diagnosis resulting from a delayed decision to refer or inefficient referral pathways can be associated with adverse consequences, such as clinical complications and a negative effect on the person's quality of life. Agreed local referral pathways should ensure rapid consultation and assessment.

Quality measures

Structure

Evidence of local referral pathways for referral of people with suspected inflammatory bowel disease for specialist assessment and investigation.

Data source: Local data collection.

Process

Proportion of people with suspected inflammatory bowel disease who are referred for specialist assessment and investigation.

Numerator – the number in the denominator who receive specialist assessment and investigation.

Denominator – the number of people with suspected inflammatory bowel disease presenting to a GP.

Data source: Local data collection.

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 ensure that local referral pathways are in place so that people with suspected inflammatory bowel disease can be referred quickly and efficiently for specialist assessment and investigation.

Healthcare professionals ensure that they follow agreed local referral pathways so that people with suspected inflammatory bowel disease are referred quickly and efficiently for specialist assessment and investigation.

Commissioners (clinical commissioning groups and NHS England area teams) 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 for specialist assessment and investigation. 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 referred to hospital so that they can be seen by a specialist for assessment. This 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 (if it is not possible to diagnose one of these, a person may be described as having 'indeterminate colitis').

Source guidance

- British Society of Gastroenterology (2011) [Guidelines for the management of inflammatory bowel disease in adults](#), section 3.3 'IBD Service Standards for diagnosis and investigation: (IBD standard A)' (page 7).

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, diarrhoea combined with rectal bleeding, or change in bowel habit [Adapted from [NICE diagnostic guidance 11](#), section 3.1]. The quality standard advisory committee noted that people with more severe symptoms might need referral before 6 weeks.

Local referral pathways

The process by which a person is referred by a GP directly to a defined person or hospital agency. [Expert opinion]

Specialist assessment and investigation

The diagnosis of inflammatory bowel disease is confirmed by clinical evaluation and a combination of biochemical, endoscopic, radiological and histological investigations. Initial laboratory investigations in common practice include full blood count, urea and electrolytes, liver function tests and erythrocyte sedimentation rate or C-reactive protein, ferritin, transferrin saturation, vitamin B12 and folate. [Adapted from [British Society of Gastroenterology guideline](#), section 3.3]

Equality and diversity considerations

The symptoms of inflammatory bowel disease may have a different impact on people from different cultures. Referral processes need to be sensitive to cultural anxieties and take into account any additional needs, such as the availability of same-sex doctors and any language barriers.

Quality statement 2: Supporting person-centred care

Quality statement

People with inflammatory bowel disease, and their family members or carers (as appropriate), are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

Rationale

The effects of inflammatory bowel disease, including the risk of associated conditions, will vary depending on the person. Discussing symptoms, treatment and management options, monitoring arrangements and multidisciplinary support (including who to contact with any concerns) with the person, leading to a personalised approach to their care, will ensure the best outcomes.

Quality measures

Structure

Evidence of local arrangements to ensure that people with inflammatory bowel disease, and their family members or carers (as appropriate), are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

Data source: Local data collection.

Process

Proportion of people with inflammatory bowel disease who have agreed monitoring arrangements relevant to their treatment with their responsible clinician.

Numerator – the number in the denominator whose monitoring arrangements, relevant to their treatment, are documented in their notes.

Denominator –the number of people with inflammatory bowel disease.

Data source: Local data collection.

Outcome

Feedback from people with inflammatory bowel disease about the quality of discussion of treatment options and arrangements for monitoring their condition and treatment.

Data source: Local data collection.

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

Service providers ensure that people with inflammatory bowel disease are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

Healthcare professionals ensure that people with inflammatory bowel disease are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

Commissioners ensure that they commission services from providers in which people with inflammatory bowel disease are supported to agree age-appropriate treatment options and monitoring arrangements with their responsible clinician.

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

People with inflammatory bowel disease are given the chance to discuss and agree options for their treatment, and arrangements for monitoring their condition and treatment, with the specialist who is looking after them. Other members of the multidisciplinary team, such as specialist nurses, surgeons and dietitians, are also involved as needed.

Source guidance

- Crohn's disease (NICE clinical guideline 152), recommendations [1.1.2](#) (key priority for implementation), [1.1.3](#), [1.1.5](#) (key priority for implementation), [1.1.6](#) (key priority for implementation), [1.2.10](#) (key priority for implementation), [1.2.11](#) (key priority for implementation), [1.3.1](#) (key priority for implementation), [1.3.2](#), [1.3.3](#), [1.6.1](#), [1.6.2](#) and [1.7.1](#).

- Ulcerative colitis (NICE clinical guideline 166), recommendations [1.1.1](#) (key priority for implementation), [1.1.2](#), [1.1.3](#), [1.2.10](#), [1.2.15](#) (key priority for implementation), [1.3.1](#) (key priority for implementation), [1.3.2](#), [1.3.3](#), [1.3.4](#), [1.3.5](#), [1.5.1](#), [1.6.1](#), [1.6.2](#), [1.6.3](#) and [1.6.4](#).

Definitions of terms used in this quality statement

Inflammatory bowel disease

The two main forms of inflammatory bowel disease are Crohn's disease and ulcerative colitis. There may be some people whose inflammatory bowel disease is classed as 'indeterminate colitis' because it has not been possible to make a definitive diagnosis of either Crohn's disease or ulcerative colitis after full examination. This quality statement can also apply to people with indeterminate colitis. [Adapted from [British Society of Gastroenterology guideline](#), section 3.1]

Age-appropriate treatment options

Treatment options for inflammatory bowel disease include drug therapy, attention to nutrition and, in severe cases or for people whose condition is not responding to treatment, surgery. Treatment options will depend on clinical severity, extent of disease, side effects, the person's tolerance of drugs and drug contraindications, the person's preferences and, in some cases, their age. Inducing and maintaining remission, as well as optimising nutritional status and growth for children and young people, and minimising psychological concerns and possible side effects of treatment, are fundamental to best practice for all people with inflammatory bowel disease, whatever their age. [Adapted from [NICE clinical guideline 152](#) and [NICE clinical guideline 166](#)]

Monitoring arrangements

Monitoring arrangements should be agreed by the inflammatory bowel disease multidisciplinary team and tailored to the person, but would normally include assessing the need for colorectal cancer surveillance, renal function and bone densitometry, as well as monitoring growth and pubertal development in children and young people. Multidisciplinary support, including dietetic support, nursing support and psychological support, should be available to all people with inflammatory bowel disease, and they should have access to a telephone service where they can raise

concerns or questions. Reviews may be carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken by a healthcare professional with relevant recognised competence in inflammatory bowel disease, such as a dietitian, nurse, health psychologist or counsellor, or gastroenterologist. The frequency of reviews should depend on the needs of the person, but as a minimum there should be an annual review for people who are not under immediate or ongoing care. [Adapted from [inflammatory bowel disease standards](#), standard A11]

Responsible clinician

The responsible clinician will depend on the stage of the inflammatory bowel disease and the type of treatment or management being provided. The responsible clinician might be, but is not limited to, a gastroenterologist, colorectal surgeon, dietitian or GP. The responsible clinician should discuss treatment options and monitoring within the multidisciplinary team (the composition of which should be appropriate for the age of the person) at every opportunity. [Adapted from [NICE clinical guideline 152](#) and [NICE clinical guideline 166](#)]

Equality and diversity considerations

Information and support to help people agree age-appropriate treatment options and monitoring should be provided in a format that is relevant to and can be understood by all people who have inflammatory bowel disease. For example, people's needs may vary according to their first language, culture, age, and whether they have a learning disability.

Question for consultation

At the Quality Standards Advisory Committee meeting, the committee discussed the importance of support for people with inflammatory bowel disease (for example, from dietitians and specialist nurses). This statement includes the concept of individualised care and support. Have we captured the important element of patient support in this draft statement and its definitions?

Quality statement 3: Surgery

Quality statement

People with inflammatory bowel disease who need surgery have it undertaken by a colorectal surgeon in a unit where the operations are performed regularly.

Rationale

The use of high-volume units where surgery for inflammatory bowel disease is performed regularly improves the likelihood of good outcomes, because of the presence of experienced surgeons, specialist nurses, access to specialist information and a pool of patients who are able to share experiences and offer mutual support. While high-volume units should be used for elective surgery, it may also be possible for people who are non-elective admissions to have surgery in high-volume units when there is time for assessment after admission.

Quality measures

Structure

Evidence of local arrangements to ensure that people with inflammatory bowel disease who have surgery have it undertaken by a colorectal surgeon in a unit where the operations are performed regularly.

Data source: Local data collection.

Process

Proportion of people with inflammatory bowel disease who have surgery undertaken by a colorectal surgeon in a unit where the operations are performed regularly.

Numerator – the number in the denominator undertaken by a colorectal surgeon in a unit where the operations are performed regularly.

Denominator – the number of elective 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.

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

Service providers ensure that surgery for inflammatory bowel disease is undertaken by a colorectal surgeon in a unit where such operations are performed regularly.

Healthcare professionals undertake surgery for inflammatory bowel disease in a unit where such operations are performed regularly, or refer people who may need surgery to colorectal surgeons in such units.

Commissioners ensure that they commission services relating to surgery for inflammatory bowel disease from providers who can demonstrate that this surgery is undertaken in a unit where such operations are performed regularly by colorectal surgeons.

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

People with inflammatory bowel disease who have surgery have their operation in a hospital where these types of operations are performed regularly, after full discussion of the benefits and risks. The operation should be carried out by a specialist surgeon called a colorectal surgeon.

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

Inflammatory bowel disease

The two main forms of inflammatory bowel disease are Crohn's disease and ulcerative colitis. There may be some people whose inflammatory bowel disease is classed as 'indeterminate colitis' because it has not been possible to make a definitive diagnosis of either Crohn's disease or ulcerative colitis after full examination. This quality statement can also apply to people with indeterminate colitis [Adapted from [British Society of Gastroenterology guideline](#), section 3.1].

Surgery

The types of operation performed on people with inflammatory bowel disease include colectomy, ileo-anal pouch procedure, ileostomy and intestinal resection. [Adapted from [NICE clinical guideline 152](#), [NICE clinical guideline 166](#) and [British Society of Gastroenterology guideline](#)]

Performed regularly

Surgical units undertaking at least 10 cases (for example, ileo-anal pouch procedures) per year as a minimum. [[British Society of Gastroenterology guideline](#), section 5.5]

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.

Use of high-volume units for surgery may mean that some people have to travel a significant distance from their home depending on local service configuration, which may make access to treatment difficult and also reduce the ability of family and friends to support people in some socioeconomic groups. The aim of the statement is to ensure that all people have access to care in high-volume units, and that access is not dependent on proximity.

Quality statement 4: Monitoring drug treatment

Quality statement

People with inflammatory bowel disease who are receiving drug treatment have the response to treatment monitored and are offered other treatment options if needed.

Rationale

People with inflammatory bowel disease may experience different responses to drug treatment, including lack of response or side effects. How a person's condition responds to drug treatment therefore needs to be monitored, and treatment amended to ensure the best outcomes.

Quality measures

Structure

Evidence of local arrangements to ensure that people with inflammatory bowel disease who are receiving drug treatment have the response to treatment monitored and are offered other treatment options if needed.

Data source: Local data collection.

Process

Proportion of people with inflammatory bowel disease who are receiving drug treatment and whose drug treatment has been reviewed.

Numerator – the number in the denominator whose drug treatment has been reviewed.

Denominator – the number of people with inflammatory bowel disease who are receiving drug treatment.

Data source: Local data collection.

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

Service providers ensure that systems are in place for monitoring drug treatment for people with inflammatory bowel disease.

Healthcare professionals ensure that they monitor responses to drug treatment for people with inflammatory bowel disease and offer other treatment options if needed.

Commissioners ensure that they commission services that monitor responses to drug treatment for people with inflammatory bowel disease and that offer alternative treatment options if needed.

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

People with inflammatory bowel disease who are having drug treatment have regular check-ups to make sure that the treatment is working and to check whether they are having any side effects, and are offered other drug treatments if there are any problems.

Source guidance

- Crohn's disease (NICE clinical guideline 152), recommendations [1.2.7](#), [1.2.8](#), [1.2.9](#), [1.2.10](#) and [1.2.11](#) (key priorities for implementation), [1.2.12](#), [1.2.14](#), [1.2.16](#) and [1.3.6](#).
- Ulcerative colitis (NICE clinical guideline 166), recommendations [1.2.7](#), [1.2.8](#), [1.2.13](#) (key priority for implementation), [1.2.15](#) (key priority for implementation) and [1.4.4](#).

Definitions of terms used in this quality statement

Inflammatory bowel disease

The two main forms of inflammatory bowel disease are Crohn's disease and ulcerative colitis. There may be some people whose inflammatory bowel disease is classed as 'indeterminate colitis' because it has not been possible to make a definitive diagnosis of either Crohn's disease or ulcerative colitis after full

examination [Adapted from [British Society of Gastroenterology guideline](#), section 3.1]. This quality statement only refers to people with a diagnosis of Crohn's disease or ulcerative colitis because the source guidance (NICE clinical guidelines 152 and 166) only covers these people.

Drug treatment

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. [Adapted from [NICE clinical guideline 152](#) and [NICE clinical guideline 166](#)]

Response to treatment

Treatment of inflammatory bowel disease aims to induce remission and control symptoms. Responses to treatment that should be monitored include improvements in a person's condition, no adequate response or an adverse response such as 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 clinical guideline 152](#) and [NICE clinical guideline 166](#)]

Full details of the 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](#).

A nominated member of staff should update patient records, act on abnormal results and communicate with people with inflammatory bowel disease (and/or their family members or carers as appropriate) and their GPs. [Adapted from [NICE clinical guideline 152](#), recommendations 1.2.10 and 1.2.11 and [NICE clinical guideline 166](#), recommendation 1.2.15]

Other treatment options

Details of treatment options for people with inflammatory bowel disease, including further interventions when there is no response or alternative treatment options

depending on the person's preference, tolerance or contraindications, can be found in [NICE clinical guideline 152](#) and [NICE clinical guideline 166](#).

Quality statement 5 (developmental): Faecal calprotectin tests

A developmental quality statement sets out what the emergent methods and processes, techniques, ideas or products are within a defined area. These are developed from NICE guidance or other sources accredited by NICE. They are not for the majority of providers and do not address areas covered by specialised commissioning; they are for those at the cutting edge of practice.

Developmental quality statement

Adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered (and in whom cancer is not suspected), and children with suspected inflammatory bowel disease who have been referred for specialist assessment, are offered faecal calprotectin testing.

Rationale

Lower gastrointestinal symptoms are common in general practice and similarities in symptoms can make it difficult for GPs to distinguish between inflammatory bowel disease and irritable bowel syndrome in adults. Specialists who are assessing children for possible inflammatory bowel disease and non-inflammatory conditions (such as irritable bowel syndrome) also need to distinguish between diseases that have similar symptoms. Faecal calprotectin testing is an emerging technology that is subject to continuing improvement. Its use in primary care should help to reduce the number of unnecessary referrals (and therefore unnecessary colonoscopies) for people with irritable bowel syndrome. It is also important to distinguish inflammatory bowel disease from non-inflammatory bowel disease so that the conditions can be managed and monitored appropriately, and complications prevented.

Implementation of faecal calprotectin testing in primary care would reduce the numbers of people being referred for specialist assessment unnecessarily, and so is related to quality statement 1.

Quality measures

Structure

a) Evidence of local arrangements to offer faecal calprotectin testing to adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered (and in whom cancer is not suspected).

Data source: Local data collection.

b) Evidence of local arrangements to offer faecal calprotectin testing to children with suspected inflammatory bowel disease who have been referred for specialist assessment.

Data source: Local data collection.

Process

a) Proportion of adults with recent-onset lower gastrointestinal symptoms who receive faecal calprotectin testing before a referral for specialist assessment.

Numerator – the number in the denominator receiving faecal calprotectin testing before referral for specialist assessment.

Denominator – the number of adults presenting with recent-onset lower gastrointestinal symptoms who are referred for specialist assessment.

Data source: Local data collection.

b) Proportion of children with suspected inflammatory bowel disease, and referred for specialist assessment, who receive faecal calprotectin testing.

Numerator – the number in the denominator receiving faecal calprotectin testing.

Denominator – the number of children with suspected inflammatory bowel disease who have been referred for specialist assessment.

Data source: Local data collection.

Outcome

a) Colonoscopy and flexisigmoidoscopy rates.

Data source: [The NHS atlas of variation in diagnostic services](#) has data on colonoscopy and flexisigmoidoscopy rates.

b) Adult referral rates for specialist assessment.

Data source: Local data collection.

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

Service providers, where possible, make faecal calprotectin testing available to adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered (and in whom cancer is not suspected), and to children with suspected inflammatory bowel disease who have been referred for specialist assessment.

Healthcare professionals, where it is available, offer faecal calprotectin testing to adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered, and to children with suspected inflammatory bowel disease who have been referred for specialist assessment.

Commissioners, where possible, commission services from providers that can demonstrate that faecal calprotectin testing is available to adults with recent-onset lower gastrointestinal symptoms for whom specialist assessment is being considered and to children with suspected inflammatory bowel disease who have been referred for specialist assessment.

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

Adults with symptoms such as abdominal pain or discomfort, bloating or a change in bowel habit that have started recently, and whose GP is considering whether to refer them to a specialist for checks for inflammatory bowel disease, may be offered a stool test that can help to determine whether the specialist checks are needed.

Children with suspected inflammatory bowel disease who have been referred to a specialist may be offered a stool test that can help to determine whether they have inflammatory or non-inflammatory bowel disease (such as irritable bowel syndrome).

Source guidance

- Faecal calprotectin diagnostic tests for inflammatory diseases of the bowel (NICE diagnostics guidance 11), recommendations [1.1](#) and [1.2](#).

Definitions of terms used in this quality statement

Recent-onset lower gastrointestinal symptoms

Symptoms that have started in the previous 6 weeks and might include abdominal pain or discomfort, bloating, diarrhoea combined with rectal bleeding or change in bowel habit. [Adapted from [NICE diagnostic guidance 11](#), section 3.1]

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, diarrhoea combined with rectal bleeding, or change in bowel habit. [Adapted from [NICE diagnostic guidance 11](#), section 3.1] The quality standard advisory committee noted that people with more severe symptoms might need referral before 6 weeks.

Specialist assessment

The diagnosis of inflammatory bowel disease is confirmed by clinical evaluation and a combination of biochemical, endoscopic, radiological or histological investigations. Initial laboratory investigations in common practice include full blood count, urea and electrolytes, liver function tests and erythrocyte sedimentation rate or C reactive protein, ferritin, transferrin saturation, vitamin B12 and folate. [Adapted from [British Society of Gastroenterology guideline](#), sections 3.3]

Faecal calprotectin testing

This is a test used to measure the level of calprotectin in stool samples (faecal calprotectin). Faecal calprotectin is a substance that is released into the intestine in excess when there is inflammation. Its presence can indicate that a person has an

inflammatory bowel disease such as Crohn's disease or ulcerative colitis. [Adapted from [NICE diagnostics guidance 11](#)]

Question for consultation

This is a 'developmental' quality standard statement relating to an emerging diagnostic technology. As a developmental statement it may be expected that it will be implemented over a longer timescale than the other statements in this quality standard because changes to patterns of service delivery may need to be put in place. Do you agree that the statement:

- represents an emergent area of practice that is only currently being carried out by a minority of providers and
- needs specific, significant changes to be put in place and
- has the potential to be widely adopted and therefore drive improvement in outcomes?

Status of this quality standard

This is the draft quality standard released for consultation from 30 April to 30 May 2014. It is not NICE's final quality standard on inflammatory bowel disease. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 30 May 2014. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from September 2014.

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'.

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.

- [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 (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 (2013) [Hospital episode statistics](#).
- Inflammatory bowel disease standards (2013) [Standards for the healthcare of people who have inflammatory bowel disease](#).
- Right Care (2013) [The NHS atlas of variation in diagnostic services](#).

Related NICE quality standards

Published

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

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.

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:

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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 for 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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