

# Coeliac disease

Quality standard

Published: 19 October 2016

[www.nice.org.uk/guidance/qs134](http://www.nice.org.uk/guidance/qs134)

# Contents

|   |    |
|---|----|
| Introduction .....  | 5  |
| Why this quality standard is needed .....   | 5  |
| How this quality standard supports delivery of outcome frameworks .....                               | 6  |
| Safety and people's experience of care .....  | 8  |
| Coordinated services.....   | 9  |
| List of quality statements.....   | 10 |
| Quality statement 1: Serological testing for coeliac disease.....                                     | 11 |
| Quality statement.....  | 11 |
| Rationale.....  | 11 |
| Quality measures .....  | 11 |
| What the quality statement means for service providers, healthcare professionals and commissioners... | 12 |
| What the quality statement means for patients and carers .....  | 13 |
| Source guidance.....  | 13 |
| Definitions of terms used in this quality statement .....   | 13 |
| Quality statement 2: Referral to a specialist.....  | 15 |
| Quality statement.....  | 15 |
| Rationale.....  | 15 |
| Quality measures .....  | 15 |
| What the quality statement means for service providers, healthcare professionals and commissioners... | 16 |
| What the quality statement means for patients and carers .....  | 16 |
| Source guidance.....  | 17 |
| Definitions of terms used in this quality statement .....   | 17 |
| Quality statement 3: Endoscopic intestinal biopsy .....   | 19 |
| Quality statement.....  | 19 |
| Rationale.....  | 19 |
| Quality measures .....  | 19 |
| What the quality statement means for service providers, healthcare professionals, and commissioners.. | 20 |

---

|   |    |
|---|----|
| What the quality statement means for patients and carers .....  | 20 |
| Source guidance.....  | 21 |
| Definitions of terms used in this quality statement .....   | 21 |
| Quality statement 4: Advice about a gluten-free diet.....   | 22 |
| Quality statement.....  | 22 |
| Rationale.....  | 22 |
| Quality measures .....  | 22 |
| What the quality statement means for service providers, healthcare professionals and commissioners... | 23 |
| What the quality statement means for patients and carers .....  | 23 |
| Source guidance.....  | 24 |
| Definitions of terms used in this quality statement .....   | 24 |
| Equality and diversity considerations.....  | 24 |
| Quality statement 5: Annual review.....   | 25 |
| Quality statement.....  | 25 |
| Rationale.....  | 25 |
| Quality measures .....  | 25 |
| What the quality statement means for service providers, healthcare professionals and commissioners... | 26 |
| What the quality statement means for patients and carers .....  | 26 |
| Source guidance.....  | 27 |
| Definitions of terms used in this quality statement .....   | 27 |
| Equality and diversity considerations.....  | 27 |
| Using the quality standard.....   | 28 |
| Quality measures .....  | 28 |
| Levels of achievement .....   | 28 |
| Using other national guidance and policy documents.....   | 28 |
| Diversity, equality and language .....  | 29 |
| Development sources.....  | 30 |
| Evidence sources.....   | 30 |

|   |    |
|---|----|
| Policy context .....  | 30 |
| Definitions and data sources for the quality measures .....     | 30 |
| Related NICE quality standards .....                            | 31 |
| Published .....   | 31 |
| In development .....  | 31 |
| Future quality standards .....                                  | 31 |
| Quality standards advisory committee and NICE project team..... | 32 |
| Quality standards advisory committee .....                      | 32 |
| NICE project team .....   | 34 |
| Update information.....   | 36 |
| About this quality standard.....                                | 37 |

This standard is based on NG20 and CG61.

This standard should be read in conjunction with QS114, QS125, QS98, QS62, QS20, QS15, QS8, QS6 and QS197.

## Introduction

This quality standard covers the recognition, assessment and management of coeliac disease in children, young people and adults. For more information, see the [coeliac disease topic overview](#).

NICE quality standards focus on aspects of health and social care that are commissioned locally. Areas of national policy, such as food labelling, are therefore not covered by this quality standard.

## Why this quality standard is needed

Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients. It is a common condition and population screening studies suggest that in the UK, 1 in 100 people are affected. The complications of coeliac disease (which may or may not be present at diagnosis) can include osteoporosis, ulcerative jejunitis, malignancy (intestinal lymphoma), functional hyposplenism, vitamin D deficiency and iron deficiency.

Coeliac disease is underdiagnosed, particularly when people present in primary care and other non-specialist settings. Delayed diagnosis is a concern because of the possible long-term complications of undiagnosed coeliac disease. People with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease. First-degree relatives of a person with coeliac disease also have an increased likelihood of having coeliac disease.

The main treatment for coeliac disease is a lifelong gluten-free diet. Most people report a rapid clinical improvement after starting a gluten-free diet. Specific education and information, such as advice on alternative foods to maintain a healthy and varied diet, may increase the likelihood of adherence and a positive prognosis.

Some people do not report symptomatic improvement after starting treatment, and some will still have persisting symptoms after 6 to 12 months. Follow-up care for people diagnosed with coeliac

disease varies widely in the UK and therefore the needs of people whose symptoms do not improve may not be addressed.

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

- diagnosis of coeliac disease
- growth in children and young people
- health-related quality of life
- incidence of osteoporosis
- incidence of intestinal lymphoma
- incidence of vitamin D deficiency
- incidence of iron deficiency.

## How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – patient safety, patient experience and clinical effectiveness – for 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 2016–17](#)
- [Public health outcomes framework for England 2016–19](#).

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 2016–17](#)

| Domain | Overarching indicators and improvement areas |
|--------|--|
|--------|--|

|   |  |
|---|--|
| <p>1 Preventing people from dying prematurely</p>   | <p><b>Overarching indicators</b></p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>i Adults</p> <p><b>Improvement areas</b></p> <p>Reducing premature mortality from the major causes of death</p> <p>1.4 Under 75 mortality rate from cancer*</p>  |
| <p>2 Enhancing quality of life for people with long-term conditions</p>   | <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>4 Ensuring that people have a positive experience of care</p>  | <p><b>Overarching indicators</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p><i>4d Patient experience characterised as poor or worse</i></p> <p><i>i Primary care</i></p> <p><b>Improvement areas</b></p> <p>Improving people's experience of outpatient care</p> <p>4.1 Patient experience of outpatient services</p> <p>Improving people's experience of integrated care</p> <p><i>4.9 People's experience of integrated care**</i></p> |
| <p><b>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p> |  |

**Table 2** Public health outcomes framework for England 2016–19

| Domain  | Objectives and indicators  |
|---|--|
| 1 Improving the wider determinants of health  | <p><b>Objective</b></p> <p>Improvements against wider factors which affect health and wellbeing and health inequalities</p> <p><b>Indicators</b></p> <p>1.03 Pupil absence</p> <p>1.09 Sickness absence rate</p>   |
| 2 Health improvement  | <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>2.11 Diet</p> <p>2.23 Self-reported wellbeing</p>   |
| 4 Healthcare public health and preventing premature mortality   | <p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p><b>Indicators</b></p> <p>4.3 Mortality rate from causes considered preventable**</p> <p>4.5 Under 75 mortality rate from cancer*</p> <p>4.13 Health-related quality of life for older people</p> <p>4.14 Hip fractures in people aged 65 and over</p> |
| <p><b>Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> |  |

## Safety and people's experience of care

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 coeliac 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. They specify 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. They also cover the provision of information to people using services. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect people's experience of using services and are specific to the topic are considered during quality statement development.

## Coordinated services

The quality standard for coeliac disease specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole coeliac disease care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with coeliac 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 coeliac 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 coeliac 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 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 coeliac 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 at increased risk or with symptoms of coeliac disease are offered a serological test for coeliac disease.

Statement 2. People with a positive serological test for coeliac disease are referred to a specialist and advised to continue with a gluten-containing diet until diagnosis is confirmed.

Statement 3. People referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease have it within 6 weeks of referral.

Statement 4. People newly diagnosed with coeliac disease discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease.

Statement 5. People with coeliac disease are offered an annual review.

# Quality statement 1: Serological testing for coeliac disease

## Quality statement

People at increased risk or with symptoms of coeliac disease are offered a serological test for coeliac disease.

## Rationale

Coeliac disease is currently underdiagnosed. If coeliac disease is not recognised, there is a risk of complications, unnecessary investigations and a poor quality of life. Offering serological testing when there is a new diagnosis for a condition that increases the risk of having coeliac disease or at presentation of symptoms of coeliac disease will improve detection and diagnosis, thereby enabling people to begin treatment.

## Quality measures

### Structure

Evidence of local arrangements to undertake serological testing for people identified with increased risk or symptoms of coeliac disease.

*Data source:* Local data collection.

### Process

a) Proportion of people at increased risk of coeliac disease who receive a serological test for coeliac disease.

Numerator – the number in the denominator who receive a serological test for coeliac disease.

Denominator – the number of people at increased risk of coeliac disease (people with type 1 diabetes or autoimmune thyroid disease at diagnosis, and first-degree relatives of people newly diagnosed with coeliac disease).

**Data source:** Local data collection. The Royal College of Paediatrics and Child Health [National Paediatric Diabetes Audit](#) collects data on coeliac disease screening in children and young people with type 1 diabetes.

b) Proportion of people with symptoms of coeliac disease who receive a serological test for coeliac disease.

Numerator – the number in the denominator who receive a serological test for coeliac disease.

Denominator – the number of people who have symptoms of coeliac disease.

**Data source:** Local data collection. To aid practicality of measurement, service providers and commissioners could focus on people presenting with symptoms of irritable bowel syndrome.

## Outcome

Diagnosed prevalence of coeliac disease.

**Data source:** Local data collection.

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

**Service providers** (for example general practices, community healthcare providers and secondary care) ensure that they take a case-finding approach to identifying coeliac disease by offering a serological test to people at increased risk or with symptoms of coeliac disease. Providers should ensure that tests for coeliac disease are only carried out when a gluten-containing diet has been followed for at least 6 weeks.

**Healthcare professionals** (such as GPs and consultants) offer a serological test for coeliac disease to people at increased risk or with symptoms of coeliac disease, and ensure that people have been following a gluten-containing diet for at least 6 weeks before the test.

**Commissioners** (such as clinical commissioning groups and NHS England) commission services that take a case-finding approach to identifying coeliac disease by offering a serological test to people at increased risk or with symptoms of coeliac disease; and ensure that they commission a pathology service that has access to the serological tests for coeliac disease.

## What the quality statement means for patients and carers

People who may have, or who are at risk of developing, coeliac disease are offered a blood test to check for the disease. It is important to diagnose coeliac disease because it can cause long-term health problems if it is not treated. Before having the test, people need to follow a diet that includes foods that contain gluten for at least 6 weeks.

### Source guidance

- [Coeliac disease: recognition, assessment and management](#) (2015) NICE guideline NG20, recommendation 1.1.1 (key priority for implementation)
- [Irritable bowel syndrome in adults: diagnosis and management](#) (2008) NICE guideline CG61, recommendation 1.1.2.1 (key priority for implementation)

## Definitions of terms used in this quality statement

### People at increased risk or with symptoms of coeliac disease

A serological test for coeliac disease should be offered to:

- people with any of the following:
  - persistent unexplained abdominal or gastrointestinal symptoms
  - faltering growth
  - prolonged fatigue
  - unexpected weight loss
  - severe or persistent mouth ulcers
  - unexplained iron, vitamin B12 or folate deficiency
  - type 1 diabetes, at diagnosis
  - autoimmune thyroid disease, at diagnosis
- adults who meet the irritable bowel syndrome diagnostic criteria

- first-degree relatives of people newly diagnosed with coeliac disease.

[[Coeliac disease](#) (NICE guideline NG20) recommendation 1.1.1 and [Irritable bowel syndrome in adults](#) (NICE guideline CG61) recommendation 1.1.2.1]

## Serological test for coeliac disease

When healthcare professionals request serological tests to investigate suspected coeliac disease in children, young people and adults, laboratories should test for total immunoglobulin A (IgA) and IgA tissue transglutaminase (tTG) as the first choice. In young people and adults, laboratories should use IgA endomysial antibodies (EMA) if IgA tTG is weakly positive and should consider using IgG EMA, IgG DGP or IgG tTG if IgA is deficient. A serological test for coeliac disease is only accurate if a gluten-containing diet has been followed for at least 6 weeks.

[Adapted from [Coeliac disease](#) (NICE guideline NG20) recommendations 1.1.3, 1.2.2 and 1.2.3]

## Quality statement 2: Referral to a specialist

### Quality statement

People with a positive serological test for coeliac disease are referred to a specialist and advised to continue with a gluten-containing diet until diagnosis is confirmed.

### Rationale

As a positive serological result for coeliac disease is not sufficient to confirm diagnosis, people should be referred to a specialist for assessment and further investigation. Confirming diagnosis will ensure that people with coeliac disease can get support to help them manage their condition.

### Quality measures

#### Structure

a) Evidence of local arrangements to ensure that people with a positive serological test for coeliac disease are referred to a specialist.

*Data source:* Local data collection.

b) Evidence of local arrangements to ensure that people referred to a specialist following a positive serological test for coeliac disease are advised to continue with a gluten-containing diet until diagnosis is confirmed.

*Data source:* Local data collection.

#### Process

a) Proportion of people with a positive serological test for coeliac disease who are referred to a specialist.

Numerator – the number in the denominator who are referred to a specialist.

Denominator – the number of people with a positive serological test for coeliac disease.

**Data source:** Local data collection.

b) Proportion of people referred to a specialist following a positive serological test for coeliac disease who are advised to continue with a gluten-containing diet until diagnosis is confirmed.

Numerator – the number in the denominator who are advised to continue with a gluten-containing diet until diagnosis is confirmed.

Denominator – the number of people referred to a specialist following a positive serological test for coeliac disease.

**Data source:** Local data collection.

## Outcome

Diagnosed prevalence of coeliac disease.

**Data source:** Local data collection.

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

**Service providers** (for example general practices, community healthcare providers and secondary care) ensure that processes are in place for people with a positive serological test for coeliac disease to be referred to a specialist and advised to continue with a gluten-containing diet until diagnosis is confirmed.

**Healthcare professionals** (such as GPs and consultants) refer people with a positive serological test for coeliac disease to a specialist and advise them to continue with a gluten-containing diet until diagnosis is confirmed.

**Commissioners** (such as clinical commissioning groups and NHS England) commission services that refer people with a positive serological test for coeliac disease to a specialist and advise them to continue with a gluten-containing diet until diagnosis is confirmed. Commissioners also ensure that an effective specialist service for people with coeliac disease has capacity to meet expected demand.

## What the quality statement means for patients and



## carers

People who have had a blood test that shows they might have coeliac disease should be referred to a specialist to have more tests to confirm whether or not they have coeliac disease. They should carry on eating foods containing gluten until they find out whether or not they have coeliac disease.

## Source guidance

- [Coeliac disease: recognition, assessment and management](#) (2015) NICE guideline NG20, recommendations 1.1.3 (key priority for implementation), 1.3.1 and 1.3.2

## Definitions of terms used in this quality statement

### Positive serological test for coeliac disease

When healthcare professionals request serological tests to investigate suspected coeliac disease, laboratories should test for total immunoglobulin A (IgA) and IgA tissue transglutaminase (tTG) as the first choice. A positive serological test result is defined as unambiguously positive IgA tTG alone, or weakly positive IgA tTG and positive IgA endomysial antibodies (EMA). In people who have IgA deficiency, a serologically positive result can be derived from any one of the IgG antibodies.

[[Coeliac disease](#) (NICE guideline NG20) recommendations 1.2.2, 1.2.3 and 1.3.1]

### Referral to a specialist

People aged 16 and over should be referred to a gastrointestinal specialist for endoscopic intestinal biopsy. Children and young people under 16 should be referred to a paediatric gastroenterologist or paediatrician with a specialist interest in gastroenterology for further investigation that may include, but is not limited to, one or more of the following:

- an endoscopic biopsy
- an IgA EMA test to confirm serological positivity
- human leukocyte antigen (HLA) genetic testing.

[[Coeliac disease](#) (NICE guideline NG20) recommendations 1.3.1 and 1.3.2]

## Gluten-containing diet

People who are following a normal diet (containing gluten) should be advised to eat gluten in more than 1 meal every day for at least 6 weeks before testing for coeliac disease.

[[Coeliac disease](#) (NICE guideline NG20) recommendation 1.1.4]

# Quality statement 3: Endoscopic intestinal biopsy

## Quality statement

People referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease have it within 6 weeks of referral.

## Rationale

A long wait for an endoscopic intestinal biopsy can mean that some people will start a gluten-free diet to relieve symptoms and will therefore not be able to complete the diagnosis process. Limiting the time that people need to continue with a gluten-containing diet to 6 weeks or less will encourage more people to complete the diagnosis process and enable them to get the support they need.

## Quality measures

### Structure

Evidence of local processes to ensure that people referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease have it within 6 weeks of referral.

*Data source:* Local data collection.

### Process

a) Proportion of people referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease who have it within 6 weeks of referral.

Numerator – the number in the denominator who have an endoscopic intestinal biopsy within 6 weeks of referral.

Denominator – the number of people referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease.

**Data source:** Local data collection.

b) Proportion of people with a positive serological test for coeliac disease who complete the diagnosis process.

Numerator – the number in the denominator who complete the diagnosis process.

Denominator – the number of people with a positive serological test for coeliac disease.

**Data source:** Local data collection.

## Outcome

Diagnosed prevalence of coeliac disease.

**Data source:** Local data collection.

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

**Service providers** (secondary care) ensure that people referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease have it within 6 weeks of referral.

**Healthcare professionals** (such as gastroenterologists and paediatricians) carry out an endoscopic intestinal biopsy to diagnose coeliac disease within 6 weeks of referral.

**Commissioners** (clinical commissioning groups) commission services with sufficient capacity to carry out an endoscopic intestinal biopsy to diagnose coeliac disease within 6 weeks of referral to a specialist.

## What the quality statement means for patients and carers

People who have had a blood test that shows they might have coeliac disease may need a biopsy to confirm the diagnosis. The biopsy should be carried out within 6 weeks of the referral. They will need to carry on eating foods containing gluten until they have had the biopsy.

## Source guidance

- [Coeliac disease: recognition, assessment and management \(2015\) NICE guideline NG20](#), recommendations 1.3.1 and 1.3.2
- The timeframe is informed by the Joint Advisory Group on GI Endoscopy guidance for non-urgent referrals.

## Definitions of terms used in this quality statement

### Referral to a specialist

People aged 16 and over should be referred to a gastrointestinal specialist. Children and young people under 16 should be referred to a paediatric gastroenterologist or paediatrician with a specialist interest in gastroenterology.

[[Coeliac disease](#) (NICE guideline NG20) recommendations 1.3.1 and 1.3.2]

# Quality statement 4: Advice about a gluten-free diet

## Quality statement

People newly diagnosed with coeliac disease discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease.

## Rationale

A gluten-free diet is the main treatment for coeliac disease. If people with coeliac disease do not follow a gluten-free diet they may experience continuing ill health and be at risk of serious long-term complications. Personalised information and advice about a gluten-free diet from a healthcare professional with specialist knowledge of coeliac disease will help people to understand and self-manage their condition.

## Quality measures

### Structure

Evidence of local arrangements to ensure that people newly diagnosed with coeliac disease discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease.

*Data source:* Local data collection.

### Process

Proportion of people newly diagnosed with coeliac disease who discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease.

Numerator – the number in the denominator who discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease.

Denominator – the number of people newly diagnosed with coeliac disease.

*Data source:* Local data collection.

## Outcome

a) Satisfaction among people with coeliac disease that they are supported to manage their condition.

*Data source:* Local data collection.

b) Health-related quality of life for people with coeliac disease.

*Data source:* Local data collection.

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

**Service providers** (for example general practices, community healthcare providers and secondary care) ensure that processes are in place for people newly diagnosed with coeliac disease to discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian.

**Healthcare professionals** (such as consultants or GPs) ensure that people newly diagnosed with coeliac disease discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian.

**Commissioners** (such as clinical commissioning groups and NHS England) commission services that ensure that people newly diagnosed with coeliac disease discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian, and that services have sufficient capacity to meet demand.

## What the quality statement means for patients and carers

**People who have coeliac disease and their carers** (if appropriate) discuss how to follow a gluten-free diet with a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian.

## Source guidance

- [Coeliac disease: recognition, assessment and management](#) (2015) NICE guideline NG20, recommendation 1.6.3 (key priority for implementation)

## Definitions of terms used in this quality statement

### Discussion about how to follow a gluten-free diet

Healthcare professionals should tell people about the importance of a gluten-free diet and give them information to help them follow it, including:

- information on which types of food contain gluten and suitable alternatives, including gluten-free substitutes
- information on which types of food are naturally gluten-free
- explanations of food labelling
- information sources about gluten-free diets, recipe ideas and cookbooks
- how to manage social situations, eating out and travelling away from home, including travel abroad
- avoiding cross contamination in the home and minimising the risk of accidental gluten intake when eating out
- the role of national and local coeliac support groups.

[[Coeliac disease](#) (NICE guideline NG20) recommendation 1.6.3 and expert opinion]

## Equality and diversity considerations

Gluten-free products are more expensive and are usually only available from larger retailers, making access more difficult for people on low incomes or with limited mobility. As coeliac disease can affect more than one member of a family it can also be an additional burden on the family budget. To address this, healthcare professionals should highlight if gluten-free food products are available on prescription to help people to maintain a gluten-free diet.



## Quality statement 5: Annual review

### Quality statement

People with coeliac disease are offered an annual review.

### Rationale

An annual review should be offered to people with coeliac disease so that adherence to a gluten-free diet and symptoms can be reviewed, information and advice about the condition and diet can be refreshed, and any further support needs can be identified. Annual reviews for children with coeliac disease also allow any impact on development to be assessed. Annual reviews provide the opportunity to identify people with refractory coeliac disease that does not improve with a gluten-free diet and to monitor any emerging long-term complications of coeliac disease.

### Quality measures

#### Structure

Evidence of local arrangements to ensure that people with coeliac disease are offered an annual review.

*Data source:* Local data collection.

#### Process

Proportion of people diagnosed with coeliac disease for more than 12 months who received an annual review in the previous 12 months.

Numerator – the number in the denominator who received an annual review in the previous 12 months.

Denominator – the number of people diagnosed with coeliac disease for more than 12 months.

*Data source:* Local data collection.

## Outcome

a) Health-related quality of life for people with coeliac disease.

*Data source:* Local data collection.

b) Identification of complications associated with coeliac disease.

*Data source:* Local data collection.

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

**Service providers** (such as general practices, community healthcare providers and secondary care) ensure that people with coeliac disease, including those discharged from secondary care, are offered an annual review and are given information about why they may need a review to encourage attendance. Service providers should consider innovative approaches to undertake reviews, including using technology to improve access to specialist advice.

**Healthcare professionals** (for example, dietitians, consultants, and GPs) offer an annual review to people with coeliac disease, including those discharged from secondary care, and encourage them to attend by giving them information about why they may need a review.

**Commissioners** (for example, clinical commissioning groups and NHS England) ensure that they commission services that offer an annual review to people with coeliac disease, including those discharged from secondary care. Commissioners encourage service providers to use innovative approaches to undertake reviews, including using technology to improve access to specialist advice.

## What the quality statement means for patients and carers

People who have coeliac disease have a check-up once a year to check their symptoms and diet, and to find out whether they need further advice or assessment.

## Source guidance

- [Coeliac disease: recognition, assessment and management](#) (2015) NICE guideline NG20, recommendation 1.4.3 (key priority for implementation)

## Definitions of terms used in this quality statement

### Annual review

An annual review for people with coeliac disease should include:

- measuring weight and height
- review of symptoms
- considering the need for assessment of diet and adherence to the gluten-free diet
- considering the need for specialist dietetic and nutritional advice
- considering the need for referral to a GP or consultant to address any concerns about possible complications or comorbidities.

[[Coeliac disease](#) (NICE guideline NG20) recommendations 1.4.3 and 1.4.4]

## Equality and diversity considerations

People living in socioeconomically deprived areas are less likely to attend an annual review. Healthcare professionals in these areas should therefore agree a local approach to encourage as many people as possible to attend.

# 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. 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 [how to use quality standards](#) for more 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.

NICE's [quality standard service improvement template](#) helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement. This tool is updated monthly to include new quality standards.

## 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 adults, children and young people with coeliac 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. Adults, children and young people with coeliac 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](#).

## 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.

- [Coeliac disease: recognition, assessment and management](#) (2015) NICE guideline NG20
- [Irritable bowel syndrome in adults: diagnosis and management](#) (2008) NICE guideline CG61

## Policy context

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

- The European Parliament and the Council of the European Union (2014) [EU FIC \(food information for consumers\) regulations on food labelling](#)
- UK National Screening Committee (2014) [The UK NSC recommendation on coeliac disease screening in adults](#)
- Food Standards Agency (2012) [Guidance on the composition and labelling of foodstuffs suitable for people intolerant to gluten](#)
- Department of Health (2005) [National service framework for long-term conditions](#)

## Definitions and data sources for the quality measures

- [Coeliac disease](#) (2015) NICE guideline NG20
- The Royal College of Paediatrics and Child Health (2014) [National Paediatric Diabetes Audit](#)
- [Irritable bowel syndrome in adults](#) (2008) NICE guideline CG61

## Related NICE quality standards

### Published

- [Diabetes in children and young people](#) (2016) NICE quality standard 125
- [Food allergy](#) (2016) NICE quality standard 118
- [Irritable bowel syndrome in adults](#) (2016) NICE quality standard 114
- [Maternal and child nutrition](#) (2015) NICE quality standard 98
- [Constipation in children and young people](#) (2014) NICE quality standard 62
- [Colorectal cancer](#) (2012) NICE quality standard 20
- [Patient experience in adult NHS services](#) (2012) NICE quality standard 15
- [Depression in adults](#) (2011) NICE quality standard 8
- [Diabetes in adults](#) (2011) NICE quality standard 6

### In development

- [Osteoporosis](#). Publication expected April 2017

## 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:

- Faltering growth
- Managing symptoms with an uncertain cause
- Thyroid disease

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 3. Membership of this committee is as follows:

**Mr Ben Anderson**

Consultant in Public Health, Public Health England

**Ms Lauren Aylott**

Lay member

**Ms Deryn Bishop**

Public Health Behaviour Change Specialist, Solihull Public Health Department

**Jan Dawson**

Registered Dietitian

**Dr Matthew Fay**

GP, Westcliffe Medical Practice, Shipley, West Yorkshire

**Dr Malcolm Fisk**

Senior Research Fellow, Centre for Computing and Social Responsibility, De Montford University, Leicester

**Ms Margaret Goose**

Lay member

**Dr Ulrike Harrower**

Consultant in Public Health Medicine, NHS Somerset

**Dr Madhavan Krishnaswamy**

Consultant Clinical Oncologist, Southend University Hospital NHS Trust



**Mrs Geeta Kumar**

Clinical Director, Women's Services (East) Betsi Cadwaladr University Health Board

**Mrs Rhian Last**

Education Lead, Education for Health, Leeds

**Mr Keith Lowe**

Head of Quality Support, Home Instead Senior Care (UK) Ltd

**Dr Hugh McIntyre (Chair)**

Consultant Physician, East Sussex Healthcare Trust

**Ms Ann Nevinson**

Lay member

**Professor Gillian Parker**

Professor of Social Policy Research, Social Policy Research Unit, University of York

**Mr David Pugh**

Independent Consultant, Gloucestershire County Council

**Dr Karen Ritchie**

Head of Knowledge and Information, Health Improvement Scotland

**Dr Eve Scott**

Head of Safety and Risk, The Christie NHS Foundation Trust, Manchester

**Mr Martin Siddorn**

Commissioning Manager, Swindon Borough Council

**Dr Susannah Solaiman**

GP and Clinical Lead for Integrated Care, Harford Health Centre, Tower Hamlets Clinical Commissioning Group

**Dr Jim Stephenson**

Consultant Medical Microbiologist, Epsom and St Helier NHS Trust

**Mr Darryl Thompson**

Registered Nurse (Mental Health), South West Yorkshire Partnership NHS Foundation Trust

**Mrs Julia Thompson**

Health Improvement Principal, Sheffield City Council

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

**Dr Mike Forrest**

GP, Karis Medical Centre, Edgbaston, Birmingham

**Ms Stephanie France**

Paediatric Dietitian, Royal Stoke University Hospital

**Dr Peter Gillett**

Consultant Paediatric Gastroenterologist, NHS Lothian

**Ms Norma McGough**

Lay member

**Miss Ruth Quinn**

Dietitian, Queen Elizabeth University Hospital, Birmingham

**Professor David Sanders**

Consultant Gastroenterologist, Royal Hallamshire Hospital, Sheffield

## **NICE project team**

**Mark Minchin**

Associate Director

**Alaster Rutherford**

Clinical Adviser

**Rachel Neary-Jones**

Programme Manager

**Craig Grime**

Technical Adviser

**Melanie Carr**  
Technical Analyst

**Esther Clifford**  
Project Manager

**Christina Barnes**  
Coordinator

# Update information

## Minor changes since publication

**December 2016:** The equality and diversity considerations section for statement 4 was amended to be clearer about the support that healthcare professionals should provide on gluten-free products.

## 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 pathway on [coeliac disease](#).

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.

ISBN: 978-1-4731-2119-5

## 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.

- [British Society of Gastroenterology](#)
- [Diabetes UK](#)
- [Coeliac UK](#)
- [Royal College of Physicians \(RCP\)](#)