NICE National Institute for
Health and Care Excellence

Coeliac disease

Quality standard
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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.

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.

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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

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

Structure

Evidence of local arrangements to 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 different audiences

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.

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. NICE guideline NG20 (2015), recommendation 1.1.1 (key priority for implementation)
- Irritable bowel syndrome in adults: diagnosis and management. NICE guideline CG61 (2008), 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:

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- 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.

[NICE's guideline on coeliac disease, recommendation 1.1.1 and NICE's guideline on irritable bowel syndrome in adults, 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 NICE's guideline on coeliac disease, 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

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

Structure

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 different audiences

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.

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. NICE guideline NG20 (2015), 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. [NICE's guideline on coeliac disease, 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.

[NICE's guideline on coeliac disease, 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. [NICE's guideline on coeliac disease, 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

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

Structure

Evidence of local 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 different audiences

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.

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. NICE guideline NG20 (2015), recommendations 1.3.1 and 1.3.2
- The timeframe is based on expert opinion.

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. [NICE's guideline on coeliac disease, 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

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

Structure

Evidence of local arrangements to ensure that people 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 different audiences

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.

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. NICE guideline NG20 (2015), 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.

[NICE's guideline on coeliac disease, 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.

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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

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

Structure

Evidence of local arrangements to ensure that people 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.

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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 different audiences

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

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to improve access to specialist advice.

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. NICE guideline NG20 (2015), 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.

[NICE's guideline on coeliac disease, 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.

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Update information

Minor changes since publication

November 2022: We updated the source guidance for timing of endoscopic intestinal biopsy in statement 3 to reflect that it is based on expert opinion.

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.

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

Information about how NICE quality standards are developed is available from the NICE website.

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

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

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

Resource impact

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

Diversity, equality and language

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

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

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Endorsing organisation

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

Supporting organisations

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

- British Society of Gastroenterology
- Diabetes UK
- Coeliac UK
- Royal College of Physicians (RCP)