Coeliac disease

NICE quality standard

Draft for consultation

February 2016

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. A key part of this quality standard is about improving the recognition and diagnosis of coeliac disease.

The treatment of 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. The quality standard therefore includes providing advice and information to support a gluten-free diet, including information about gluten-free staple foods available on prescription.

People with coeliac disease are at risk of complications and may have coexisting conditions. 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. The quality standard therefore ensures that people with coeliac disease are offered an annual review.

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 2015–16
- Public Health Outcomes Framework 2013–16.

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2015–16

Domain	**Overarching indicators and improvement areas**
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer*
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services *4d Patient experience characterised as poor or worse* *i Primary care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 **Public health outcomes framework for England, 2013–16**

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.3 Mortality rate from causes considered preventable** 4.5 Under 75 mortality rate from cancer* 4.13 Health-related quality of life for older people 4.14 Hip fractures in people aged 65 and over
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary	

Patient experience and safety issues

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to 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 patients and service users. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect patient experience 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 for further investigation and advised to continue with a gluten-containing diet until diagnosis is confirmed.

Statement 3. People diagnosed with coeliac disease are given advice about a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease.

Statement 4. People diagnosed with coeliac disease are informed about the gluten-free foods available on prescription.

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

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 Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these systems and structures to be put in place?

Question 3 Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

Question 4 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Questions about the individual quality statements

Question 5 For draft quality statement 2: Is it reasonable to suggest that an endoscopic intestinal biopsy should be carried out within 6 weeks of referral to ensure that people have a time limit for continuing with a gluten-containing diet?

Question 6 For draft quality statement 4: Are people with coeliac disease currently being informed about the gluten-free foods available on prescription? Please explain your answer.

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. A proactive approach to serological testing for people with an increased risk or symptoms of coeliac disease will improve detection and diagnosis, thereby enabling people to begin treatment.

Quality measures

Structure

a) Evidence of local arrangements to identify people with increased risk or symptoms of coeliac disease.

Data source: Local data collection.

b) 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.

Data source: Local data collection. The Royal College of Paediatrics and Child Health National Paediatric Diabetes Audit collects data on coeliac disease monitoring in children and young people with 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

Rate of diagnosis 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 proactive, 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.

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 before the test.

Commissioners (such as clinical commissioning groups and NHS England) commission services that take a proactive, 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, service users 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 have been following a diet that includes foods that contain gluten.

Source guidance

- Coeliac disease (2015) NICE guideline NG20, recommendations 1.1.1 and 1.1.3 (key priorities for implementation)

Definitions of terms used in this quality statement

People at increased risk of coeliac disease

A serological test for coeliac disease should be offered to:

- people with type 1 diabetes, at diagnosis
- people with autoimmune thyroid disease, at diagnosis
- first-degree relatives of people newly diagnosed with coeliac disease.

[Coeliac disease (NICE guideline NG20) recommendation 1.1.1]

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
- adults with irritable bowel syndrome

[Coeliac disease (NICE guideline NG20) recommendation 1.1.1]

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. A serological test for coeliac disease is only accurate if a gluten -containing diet has been followed. [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 for further investigation 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 to consider further investigation, such as endoscopic intestinal biopsy. People should be advised to continue with a gluten-containing diet until diagnosis is confirmed, to ensure that any further investigations are accurate.

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 for further investigation.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that people referred to a specialist for further investigation 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 for further investigation.

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

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 for further investigation 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 for further investigation following a positive serological test for coeliac disease.

Data source: Local data collection.

Outcome

Rate of diagnosis 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 for further investigation 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 for further investigation and advise them to continue with a gluten-containing diet until diagnosis is confirmed. They should also ensure an effective specialist service for people with coeliac disease has capacity to meet expected demand.

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

People who have had a blood test that shows they might have coeliac disease should be referred to a specialist to discuss having more tests to confirm whether or not they have coeliac disease. Adults, children and young people should carry on eating foods containing gluten until they are told whether or not they have coeliac disease.

Source guidance

- Coeliac disease (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 in children, young people and adults, 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 a positive IgA endomysial antibodies (EMA) test result. 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 for further investigation

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, 1 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]

Question for consultation

Is it reasonable to suggest that an endoscopic intestinal biopsy should be carried out within 6 weeks of referral to ensure that people have a time limit for continuing with a gluten-containing diet?

Quality statement 3: Advice about a gluten-free diet

Quality statement

People diagnosed with coeliac disease are given advice about a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease.

Rationale

A gluten-free diet is the only treatment for coeliac disease. 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 diagnosed with coeliac disease are given advice about a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease.

Data source: Local data collection.

Process

Proportion of people diagnosed with coeliac disease who receive advice about a gluten-free diet from a healthcare professional with specialist knowledge of coeliac disease.

Numerator – the number in the denominator who receive advice about a gluten-free diet from 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) People with coeliac disease are confident they are able to follow a gluten-free diet.

Data source: Local data collection.

b) Health-related quality of life.

Data source: Local data collection. NHS England's GP patient survey includes questions on health-related quality of life.

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 diagnosed with coeliac disease to be given advice about a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian.

Healthcare professionals (such as consultants or GPs) ensure that people diagnosed with coeliac disease are given advice about a gluten-free diet by 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 diagnosed with coeliac disease are given advice about a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian, and that services have sufficient capacity to deliver this advice.

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

People who have coeliac disease are given advice to help them follow a gluten-free diet by a healthcare professional with specialist knowledge of coeliac disease, such as a dietitian.

Source guidance

- Coeliac disease (2015) NICE guideline NG20, recommendation 1.6.3 (key priority for implementation)

Definitions of terms used in this quality statement

Advice about 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
- 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]

Equality and diversity considerations

Healthcare professionals should take into account cultural and communication needs (including any learning disabilities) when giving advice about a gluten-free diet.

Quality statement 4: Information about gluten-free foods available on prescription

Quality statement

People diagnosed with coeliac disease are informed about the gluten-free foods available on prescription.

Rationale

Gluten-free products are more expensive and are usually only available from larger retailers. Prescriptions for gluten-free food can be important to help people to maintain a gluten-free diet. Giving people information about the products available on prescription and the quantity that can be prescribed will help people to plan their diet and self-manage their condition.

Quality measures

Structure

Evidence of local arrangements to ensure that people diagnosed with coeliac disease are informed about the gluten-free foods available on prescription.

Data source: Local data collection.

Process

Proportion of people diagnosed with coeliac disease who are informed about the gluten-free foods available on prescription.

Numerator – the number in the denominator who are informed about the gluten-free foods available on prescription.

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

Data source: Local data collection.

Outcome

Adherence to a gluten-free diet among people 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 pharmacies, community healthcare providers and secondary care) ensure that people diagnosed with coeliac disease are informed about the gluten-free foods available on prescription.

Healthcare professionals (such as GPs, community pharmacists and dietitians) give information about the gluten-free foods available on prescription to people who are diagnosed with coeliac disease.

Commissioners (such as clinical commissioning groups and NHS England) commission services that ensure that people diagnosed with coeliac disease are informed about the gluten-free foods available on prescription.

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

People who have coeliac disease are given information about the gluten-free foods that they can get on prescription to help them to follow a gluten-free diet.

Source guidance

- Coeliac disease (2010) NICE clinical knowledge summary, prescribing information

Definitions of terms used in this quality statement

Gluten-free foods available on prescription

Gluten-free foods approved for prescription by the Advisory Committee on Borderline Substances can be found on the Coeliac UK website and in the British National Formulary and the British National Formulary for children.

Equality and diversity considerations

Access to gluten-free food may be more difficult for people on low incomes. Healthcare professionals should, therefore, offer additional support to help them find suitable products on prescription to encourage them to maintain a gluten-free diet.

Question for consultation

Are people with coeliac disease currently being informed about the gluten-free foods available on prescription? Please explain your answer.

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 their 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 should also assess any impact on their development. 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.

Data source: Local data collection. NHS England's GP patient survey includes questions on health-related quality of life.

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 pharmacists, 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.

Healthcare professionals (for example, dietitians, consultants, GPs and community pharmacists) 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.

What the quality statement means for patients, service users 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 any further advice or assessment.

Source guidance

- Coeliac disease (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]

Status of this quality standard

This is the draft quality standard released for consultation from 25 February to 24 March 2016. It is not NICE's final quality standard on coeliac 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 24 March 2016. 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 October 2016.

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.

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.

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 (2015) NICE guideline NG20
- Coeliac disease (2010) NICE clinical knowledge summary, prescribing information

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
- NHS England (2015) GP patient survey
- The Royal College of Paediatrics and Child Health (2013/14) National Paediatric Diabetes Audit

Related NICE quality standards

Published

- 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
- Anxiety disorders (2014) NICE quality standard 53
- 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

- Food allergy and anaphylaxis due to any cause. Publication expected March 2016
- Diabetes in children and young people. Publication expected June 2016

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
- Osteoporosis
- 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:

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

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Paediatric Dietitian, Royal Stoke University Hospital

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Ms Norma McGough

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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 will be incorporated into the NICE pathway on coeliac disease.

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