

Fetal alcohol spectrum disorder

Quality standard

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Contents

Quality statements	4
Quality statement 1: Advice on avoiding alcohol in pregnancy	5
Quality statement	5
Rationale	5
Quality measures	5
What the quality statement means for different audiences	6
Source guidance	7
Quality statement 2: Fetal alcohol exposure	8
Quality statement	8
Rationale	8
Quality measures	8
What the quality statement means for different audiences	10
Source guidance	10
Quality statement 3: Referral for assessment	11
Quality statement	11
Rationale	11
Quality measures	11
What the quality statement means for different audiences	12
Source guidance	13
Definitions of terms used in this quality statement	14
Quality statement 4: Neurodevelopmental assessment	16
Quality statement	16
Rationale	16
Quality measures	16
What the quality statement means for different audiences	17
Source guidance	17
Definitions of terms used in this quality statement	18

Quality statement 5: Management plan 20

 Rationale..... 20

 Quality measures 20

 What the quality statement means for different audiences..... 21

 Source guidance..... 22

About this quality standard..... 23

 Resource impact 23

 Diversity, equality and language 23

This standard is based on NG201 and PH24.

Quality statements

Statement 1 Pregnant women are given advice throughout pregnancy not to drink alcohol.

Statement 2 Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.

Statement 3 Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.

Statement 4 Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.

Statement 5 Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs.

Quality statement 1: Advice on avoiding alcohol in pregnancy

Quality statement

Pregnant women are given advice throughout pregnancy not to drink alcohol.

Rationale

Drinking alcohol during pregnancy increases the risk of harm to the baby. There is no known safe level of alcohol consumption during pregnancy and the [UK Chief Medical Officers' low-risk drinking guidelines](#) state that the safest approach is to avoid alcohol altogether to minimise risks to the baby. Midwives and other healthcare professionals should give women clear and consistent advice on avoiding alcohol throughout pregnancy, and explain the benefits of this, including preventing fetal alcohol spectrum disorder (FASD) and reducing the risks of low birth weight, preterm birth and the baby being small for gestational age.

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 midwives and other healthcare professionals carrying out antenatal appointments are aware of the risks of drinking alcohol in pregnancy, including FASD, and the advice in the [UK Chief Medical Officers' low-risk drinking guidelines](#) on alcohol consumption in pregnancy.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from staff training records.

b) Evidence of local arrangements to ensure that antenatal appointments include discussion of the risks of drinking alcohol in pregnancy and the advice in the [UK Chief Medical Officers' low-risk](#)

drinking guidelines.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from appointment schedules and information given to pregnant women about what is covered in their antenatal appointments.

Process

Proportion of antenatal appointments in which pregnant women are advised not to drink alcohol during pregnancy.

Numerator – the number in the denominator in which pregnant women are advised not to drink alcohol.

Denominator – the total number of antenatal appointments attended.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, maternity records. Achievement levels should be agreed locally based on population needs.

Outcome

Rate of alcohol-exposed pregnancies.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of maternity records. The [NHS Digital Maternity Services Data Set](#) includes information on alcohol consumption recorded at the antenatal booking appointment. The [Perinatal Institute's Pregnancy notes](#) record information on alcohol consumption in pregnancy.

What the quality statement means for different audiences

Service providers (maternity services) ensure that midwives and other healthcare professionals providing antenatal care are aware of the risks to the fetus of drinking alcohol in pregnancy, and

have training on FASD awareness and alcohol brief interventions. They ensure that antenatal appointments include verbal and written advice not to consume alcohol in pregnancy, based on the [UK Chief Medical Officers' low-risk drinking guidelines](#).

Healthcare professionals (midwives, nurses, doctors and health visitors) discuss with pregnant women the risks to the fetus of drinking alcohol in pregnancy and provide support at antenatal appointments. They provide verbal and written advice, based on the [UK Chief Medical Officers' low-risk drinking guidelines](#), that the safest approach is to avoid drinking any alcohol during pregnancy. This includes information that the risk of harm to the baby is likely to be low if only small amounts of alcohol have been consumed but that further drinking should be avoided. They use a non-judgemental approach, discuss any concerns and provide support according to the woman's needs, which may include a structured conversation, help to stop drinking through a brief intervention and signposting, or referral to specialist services.

Commissioners (such as clinical commissioning groups, integrated care systems and NHS England) commission maternity services that give advice at antenatal appointments about not drinking alcohol during pregnancy. They commission services for pregnant women who continue to drink but are not alcohol dependent and for those who are alcohol dependent.

Pregnant women discuss the risks of drinking in pregnancy with their midwife or healthcare professional at antenatal appointments throughout their pregnancy. Their healthcare professional explains the benefits to the baby of avoiding alcohol, including preventing fetal alcohol spectrum disorder (FASD), and advises that the safest approach is to not drink alcohol at all. If they are worried about already having drunk alcohol during pregnancy or want support to stop drinking, they are reassured and offered further help.

Source guidance

- [Antenatal care. NICE guideline NG201](#) (2021), recommendations 1.1.2 and 1.3.10
- [Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156](#) (2019), recommendation 2.1 page 11

Quality statement 2: Fetal alcohol exposure

Supporting women to make decisions about their care is important during pregnancy. Healthcare professionals should ensure that women have the information they need to make decisions and to give consent in line with [General Medical Council \(GMC\) guidance](#) and the [Nursing and Midwifery Council \(NMC\) Code](#).

Quality statement

Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.

Rationale

Talking about and recording alcohol consumption during pregnancy allows personalised discussions about the risks of alcohol use as part of routine healthcare throughout pregnancy. It also gives opportunities to offer tailored support and interventions if the woman wishes to cut down or stop drinking. This may reduce risks and improve outcomes for the mother and baby. Women should be asked about their alcohol consumption in a sensitive, non-judgemental way. Women who wish to discuss their alcohol use should be asked about the quantity, frequency and pattern of drinking, and this should be documented in their maternity records. This information may also help support early diagnosis and treatment for children with fetal alcohol spectrum disorder (FASD).

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 antenatal appointments include discussion about drinking alcohol in pregnancy.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from appointment schedules and information given to pregnant women about what is covered in their antenatal appointments.

Process

a) Proportion of antenatal booking appointments where drinking of alcohol is reported.

Numerator – the number in the denominator where the weekly number of alcohol units reported is greater than 1.

Denominator – the number of antenatal booking appointments.

Data source: The [NHS Digital Maternity Services Data Set](#) includes information on the weekly number of alcohol units reported at the antenatal booking appointment. [Public Health Outcomes Framework](#) indicator C03b – 'Drinking in early pregnancy' presents this measure at national and local authority level.

b) Proportion of routine antenatal appointments attended in which alcohol consumption is recorded.

Numerator – the number in the denominator in which alcohol consumption is recorded.

Denominator – the total number of routine antenatal appointments attended.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of maternity records. The [NHS Digital Maternity Services Data Set](#) includes information on alcohol consumption recorded at the antenatal booking appointment. The [Perinatal Institute's Pregnancy notes](#) record information on alcohol consumption in pregnancy.

Outcome

Diagnosis rates for FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider

organisations, for example, from local audits of patient records.

What the quality statement means for different audiences

Service providers (maternity services) ensure that antenatal appointments include discussion and recording of alcohol consumption in pregnancy. They ensure that midwives providing antenatal care are aware of the risks to the fetus of drinking alcohol in pregnancy, and have training on FASD awareness and alcohol brief interventions.

Healthcare professionals (midwives, nurses and doctors) ask pregnant women about their alcohol consumption and discuss the associated risks. They use a non-judgemental approach, discuss any concerns and provide support according to the woman's needs. They record information on a woman's alcohol consumption during pregnancy in her maternity records at antenatal appointments, including the number and types of alcoholic drinks consumed, as well as the pattern and frequency of drinking.

Commissioners (such as clinical commissioning groups or integrated care systems) commission maternity services that discuss alcohol use during pregnancy at antenatal appointments and record it in the mother's maternity records. They commission services for pregnant women who continue to drink but are not alcohol dependent and for those who are alcohol dependent.

Pregnant women are asked at antenatal appointments about any alcohol they have drunk during pregnancy. They have a discussion with their midwife about the risks of drinking alcohol while pregnant, and are asked if they have any concerns or would like further information. Women who continue to drink are offered support if they wish to stop drinking. Information about these discussions, including their alcohol use, is documented in their maternity records.

Source guidance

- [Antenatal care. NICE guideline NG201](#) (2021), recommendations 1.2.11 and 1.3.10
- [Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156](#) (2019), recommendations 2.1 (page 11) and 2.1.2 (page 12)
- [Alcohol-use disorders: prevention. NICE guideline PH24](#) (2010), recommendation 9

Quality statement 3: Referral for assessment

Quality statement

Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.

Rationale

When children and young people present with developmental problems, prenatal alcohol exposure is often not considered as a possible cause, especially if they do not have the characteristic facial features of prenatal alcohol exposure. This results in inconsistency in referring children and in the assessments they are offered. Referral for assessment can lead to different investigations and a range of outcomes including diagnosis of fetal alcohol spectrum disorder (FASD) or another neurodevelopmental disorder, or identification of an impairment not associated with any specific diagnosis.

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 pathways that refer children and young people with probable prenatal alcohol exposure to a healthcare professional with additional training in FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications, NHS trust directories of services and clinical commissioning group pathways.

b) Evidence of local arrangements to increase awareness of FASD among healthcare professionals.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider

organisations, for example, from staff training programmes and learning resources directories.

c) Evidence of local services with healthcare professionals who have additional training in FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications, NHS trust directories of services and clinical commissioning group pathways.

Process

Proportion of children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties referred for assessment.

Numerator – the number in the denominator referred for assessment.

Denominator – the number of children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

Outcome

a) Average time to diagnosis of FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

b) Diagnosis rates for FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

What the quality statement means for different

audiences

Service providers (such as primary care services, community paediatric services, child development centres, and child and adolescent mental health services) provide training in FASD to healthcare professionals. Primary care services give training to GPs to raise awareness of prenatal alcohol exposure as a possible cause of neurodevelopmental disorders. Community paediatric services, child development centres, and child and adolescent mental health services have training programmes for healthcare professionals on assessing and diagnosing FASD. They establish multidisciplinary teams and multidisciplinary approaches, and develop referral pathways for assessment.

Healthcare and education professionals (such as GPs, special educational needs coordinators, school nurses and health visitors) refer children and young people with significant physical, developmental or behavioural difficulties and probable prenatal alcohol exposure for an assessment that considers prenatal alcohol exposure as a possible cause. Referral is to community paediatric services, child development centres or child and adolescent mental health services for assessment by a healthcare professional with additional training in FASD. They discuss the need for referral with sensitivity, recognising the need to avoid anxiety and stigma.

Commissioners (such as clinical commissioning groups, integrated care systems and NHS England) commission services that consider prenatal alcohol exposure as a possible cause of neurodevelopmental disorders when assessing children and young people with significant physical, developmental or behavioural difficulties. They develop pathways for referring children and young people to healthcare professionals with additional training in FASD.

Children and young people with significant physical, developmental or behavioural problems that affect their daily activities who may have been exposed to alcohol before birth are referred for an assessment by a healthcare professional with additional training in FASD.

Source guidance

Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156 (2019), recommendation 2.1.4 page 14

Definitions of terms used in this quality statement

Probable prenatal alcohol exposure

This can be based on information suggesting it is likely there has been alcohol exposure during pregnancy, such as:

- reliable clinical observation
- self-report or report by a reliable source
- medical records documenting positive blood alcohol concentrations
- treatment for alcohol-related problems.

The presence of all 3 facial sentinel features (short palpebral fissures, smooth philtrum and thin upper lip) has high specificity for prenatal alcohol exposure and FASD which means that confirmation of alcohol exposure is not needed when all 3 are present. [Adapted from [Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol](#), recommendations 2.1.1 (page 11) and 3.1.1 (page 15)]

Significant physical, developmental or behavioural difficulties

Physical, behavioural and neurodevelopmental difficulties associated with FASD include:

- abnormalities in how the brain works, which can show up in different ways, such as problems with learning, attention, memory or language, difficulty with abstract concepts, poor problem-solving skills, difficulty in learning from consequences and confused social skills
- physical effects such as a smaller head circumference, damage to the structure of the brain, heart or kidney problems, vision or hearing impairment and characteristic facial features.

Significant indicates that the difficulties are disrupting the ability of the child, young person or their family to function and carry out activities of daily living. [Adapted from [Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol](#), supporting material (information on FASD) and expert opinion]

Assessment

A process which considers prenatal alcohol exposure as a cause of possible neurodevelopmental disorder. It includes a review of family, social and medical history and a complete physical

examination. [Adapted from Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol, recommendations 2.1.4 (page 14) and 3.2 (page 17)]

Quality statement 4: Neurodevelopmental assessment

Quality statement

Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.

Rationale

Fetal alcohol spectrum disorder (FASD) is one possibility when prenatal alcohol exposure is being considered as a cause of neurodevelopmental disorder. A neurodevelopmental assessment is needed to confirm, or rule out, a diagnosis of FASD. The neurodevelopmental issues associated with FASD are complex and varied, so the specific aspects of the assessment and the professionals involved will vary. Confirmation of a diagnosis of FASD (or risk of FASD) ensures the child or young person receives the right treatment, care and support while plans for longer-term management are being made.

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 services with healthcare professionals with expertise in neurodevelopmental assessment who have had additional training in FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from service specifications, NHS trust directories of services and clinical commissioning group pathways.

Outcome

Diagnosis rate for FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

What the quality statement means for different audiences

Service providers (such as community paediatric services, child development centres, and child and adolescent mental health services) ensure healthcare professionals with expertise in neurodevelopmental assessments have additional training in FASD. They enable professionals to join multidisciplinary teams that may be local, central or virtual.

Healthcare professionals (such as community paediatricians, psychiatrists, psychologists, clinical psychologists, paediatric neuropsychologists, speech and language therapists, and occupational therapists) are involved in neurodevelopmental assessment of children and young people with prenatal alcohol exposure if there are clinical concerns about their physical, developmental or behavioural difficulties. The assessment covers the areas of brain function known to be affected by prenatal alcohol exposure with the aim of making a diagnosis and developing a management plan. When diagnosing FASD, healthcare professionals should create an environment that supports all those affected, and avoid blaming, stigmatising and inducing feelings of guilt in the parents.

Commissioners (such as clinical commissioning groups or integrated care systems) commission services for neurodevelopmental assessments that consider FASD as a diagnosis.

Children and young people who are known to have been exposed to alcohol before birth or have all 3 facial features suggesting this have a more detailed assessment if there are concerns. Different healthcare professionals may be involved in assessing their motor skills (movement), language, cognition (thinking and reasoning) and their ability to manage emotions.

Source guidance

Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156 (2019), recommendation 3.5 page 23

Definitions of terms used in this quality statement

Confirmed prenatal alcohol exposure

Documentation that the biological mother consumed alcohol during pregnancy based on:

- reliable clinical observation
- self-report or report by a reliable source
- medical records documenting positive blood alcohol concentrations
- treatment for alcohol-related problems.

The presence of all 3 facial sentinel features (short palpebral fissures, smooth philtrum and thin upper lip) has high specificity for prenatal alcohol exposure and FASD which means that confirmation of alcohol exposure is not needed when all 3 are present. [Adapted from [Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol](#), recommendations 2.1.1 (page 11) and 3.1.1 (page 15)]

Neurodevelopmental assessment

An assessment by a multidisciplinary team to confirm or exclude a diagnosis of FASD covering:

- motor skills
- neuroanatomy or neurophysiology
- cognition
- language
- academic achievement
- memory
- attention
- executive function, including impulse control and hyperactivity
- affect regulation
- adaptive behaviour, social skills or social communication.

FASD diagnosis requires the ruling out of other aetiological factors, for example, genetic and associated comorbidities. A diagnosis of FASD can only be made when there is evidence of pervasive and long-standing brain dysfunction in 3 or more of the above areas of neurodevelopmental assessment.

Full details, including method of assessment and special considerations are set out in the source guideline. [Adapted from [Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol](#), recommendation 3.4.1 (page 19) and expert opinion]

Clinical concerns

Significant behavioural issues causing disruption to family and school, developmental delays that are affecting the child or young person's life, and failure to thrive physically and emotionally.
[Expert opinion]

Quality statement 5: Management plan

Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs.

Rationale

An individualised management plan sets out the intervention and support needs identified during assessment and diagnosis of FASD. The plan signposts the child or young person with FASD and their family to resources and services. It covers the basic and immediate needs of the child or young person after assessment as well as their long-term needs. Because FASD has lifelong effects, a staged management plan may be needed to anticipate upcoming problems at planned intervals and revision should be considered at all transition stages in the person's life. A management plan also helps people with FASD, their families, carers and service providers to understand and address the associated challenges. The plan helps to coordinate care across a range of healthcare professionals, as well as education and social services, and improves outcomes.

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 frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications and service protocols.

b) Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider

organisations, for example, from service protocols.

Process

Proportion of children and young people diagnosed with FASD who have a management plan.

Numerator – the number in the denominator who have a management plan.

Denominator – the number of children and young people diagnosed with FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records. The [Scottish Intercollegiate Guidelines Network's sample FASD management plan](#) has been produced to support the source guideline.

Outcome

Health-related quality of life for people diagnosed with FASD.

Data source: No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, a survey of people with FASD using a quality of life questionnaire.

What the quality statement means for different audiences

Service providers (such as community paediatric services, child development centres, and child and adolescent mental health services) have training programmes for healthcare professionals on managing FASD. They establish frameworks for managing FASD that allow healthcare professionals to work across disciplines and organisations, and they provide information on the effects of FASD to education and social services.

Healthcare professionals (such as paediatricians, psychologists and psychiatrists) develop a management plan for children and young people diagnosed with FASD. They discuss with the children, young people and their families their priorities and goals to be included in the plan, and who the plan should be shared with. They identify interventions and support to address the particular needs of the child or young person, including further referrals and education support.

Commissioners (such as clinical commissioning groups, integrated care systems and NHS England) ensure that they commission services that provide a management plan and support for children and young people diagnosed with FASD.

Children and young people with FASD and their parents or carers develop a management plan with the team who carried out the assessments before their diagnosis. They discuss what the plan should cover, their priorities and goals, and who the plan should be shared with.

Source guidance

Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156 (2019), recommendation 3.6.2 (page 24), 4.1.1 (page 27) and 4.1.2 (pages 27 to 28)

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 standard advisory committees](#) for details of standing committee 2 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on 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.

Diversity, equality and language

During the development of this quality standard, equality issues were considered 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)