NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Fetal alcohol spectrum disorder

NICE quality standard

Draft for consultation

5 March 2020

Please note that this is an extension to the consultation exercise which was held from 6 March to 3 April 2020. The content of the quality standard remains unchanged apart from this box. If your organisation commented previously, you do not need to resubmit your comments. However, if you have additional comments that you would like to submit, you are welcome to.

This quality standard covers assessing and diagnosing fetal alcohol spectrum disorder in children and young people. It also covers alcohol consumption during pregnancy. It describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 20 August to 18 September 2020). The final quality standard is expected to publish in January 2021.

Quality statements

Statement 1 Pregnant women are given advice not to drink alcohol during pregnancy at their first contact appointment.

Statement 2 Pregnant women have information on their alcohol consumption recorded throughout their pregnancy.

Statement 3 Children and young people with physical, developmental or behavioural difficulties and probable prenatal alcohol exposure 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.

Other quality standards that should be considered when commissioning or providing fetal alcohol spectrum disorder services include:

- Developmental follow-up of children and young people born preterm NICE quality standard 169
- Antenatal and postnatal mental health NICE quality standard 115
- Postnatal care NICE quality standard 37
- Antenatal care NICE quality standard 22
- Alcohol-use disorders: diagnosis and management NICE quality standard 11

A full list of NICE quality standards is available from the quality standards topic library.

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 data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

Question 3 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed 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.

Local practice case studies

Question 4 Do you have an example from practice of implementing the guideline that underpins this quality standard? If so, please provide details on the comments form.

Quality statement 1: Advice on alcohol consumption in pregnancy

Quality statement

Pregnant women are given advice not to drink alcohol during pregnancy at their first contact appointment.

Rationale

Fetal alcohol spectrum disorder (FASD) can be prevented if a woman avoids drinking alcohol during pregnancy. There is no known safe level of alcohol consumption during pregnancy. 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. Pregnant women need clear and consistent advice on alcohol. The first contact appointment with a midwife or doctor in pregnancy is the earliest opportunity for a healthcare professional to give this.

Quality measures

Structure

a) Evidence of local arrangements to ensure that midwives and doctors carrying out antenatal appointments are aware of advice in the UK Chief Medical Officers' low-risk drinking guidelines on alcohol consumption in pregnancy.

Data source: Local data collection, for example, staff training records.

b) Evidence of local arrangements to ensure that midwives and doctors carrying out antenatal appointments are aware of the risks of drinking alcohol in pregnancy including the risks of FASD.

Data source: Local data collection, for example, staff training records.

c) Evidence of local arrangements to ensure that first contact 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: Local data collection, for example, appointment schedules, patient information detailing the content of antenatal appointments.

Process

Proportion of pregnant women attending a first contact appointment who are given advice not to drink alcohol during pregnancy.

Numerator – the number in the denominator given advice not to drink alcohol during pregnancy.

Denominator – the number of pregnant women attending a first contact appointment.

Data source: Local data collection, for example, maternity records.

Outcome

Alcohol consumption rates in pregnancy.

Data source: Local data collection, for example, local audit of maternity records. The NHS digital Maternity Services Data Set includes information on alcohol consumption recorded in pregnancy. The Perinatal Institute Pregnancy notes also record information on alcohol consumption in pregnancy.

What the quality statement means for different audiences

Service providers (maternity services and GP practices) ensure that midwives and doctors providing antenatal care are aware of the risks to the fetus of drinking alcohol in pregnancy. They ensure that first contact 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 and GPs) discuss with pregnant women the risks to the fetus of drinking alcohol in pregnancy at the first contact appointment. They provide verbal and written advice based on the UK Chief Medical Officers' low-risk drinking guidelines that the safest approach is to avoid alcohol altogether in pregnancy. They use a non-judgemental approach, discuss any concerns and ensure supportive follow-up care if needed, such counselling or help to stop drinking.

Commissioners (such as clinical commissioning groups and NHS England) commission maternity and primary care services that give advice at the first contact appointment not to drink alcohol during pregnancy.

Pregnant women have a discussion with their midwife or doctor about the risks of drinking in pregnancy. This includes the risks to their baby. The discussion happens at their first appointment during pregnancy. They are advised that the safest approach is not to drink alcohol at all. If they are worried about already having drunk alcohol during pregnancy or they want support to stop drinking, they are offered further help.

Source guidance

- Children and young people exposed prenatally to alcohol. Scottish Intercollegiate Guidelines Network guideline SIGN 156 (2019), recommendation 2.1 page 11
- Antenatal care for uncomplicated pregnancies NICE guideline CG62 (2008), recommendation 1.1.1.1

Quality statement 2: Maternal alcohol use in pregnancy

Quality statement

Pregnant women have information on their alcohol consumption recorded throughout their pregnancy.

Rationale

Identifying children at risk of fetal alcohol spectrum disorder (FASD) depends on accurate recording of a mother's alcohol consumption during pregnancy. A lack of this information is a barrier to a diagnosis of FASD and, in the absence of 3 sentinel facial features, prevents a diagnosis being made. Antenatal appointments allow questions on alcohol consumption to be asked as part of routine healthcare throughout pregnancy. The timing, quantity and frequency of alcohol use should be recorded in maternity records and then transferred to the child's health records after birth. This is particularly important for children no longer with their biological mother (such as adopted children and looked-after children).

Quality measures

Structure

a) Evidence of local arrangements to ensure that antenatal appointments include discussion on drinking alcohol in pregnancy.

Data source: Local data collection, for example, appointment schedules, patient information detailing the content of antenatal appointments.

b) Evidence of local proformas or templates for maternity records which include sections to document information on alcohol consumption during pregnancy.

Data source: Local data collection, for example, maternity records, guidance on what to include in maternity records.

c) Evidence of local arrangements to ensure that maternity services transfer information on a mother's alcohol consumption in pregnancy to her child's health record after the birth.

Data source: Local data collection, for example, transfer of care documentation.

Process

a) Proportion of antenatal appointments attended where alcohol consumption is recorded.

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

Denominator – the number of antenatal appointments attended.

Data source: Local data collection, for example, local audit of maternity records. The NHS digital Maternity Services Data Set includes information on alcohol consumption recorded at the antenatal booking appointment. The Perinatal Institute Pregnancy notes record information on alcohol consumption in pregnancy.

b) Proportion of births with information on the mother's alcohol consumption in pregnancy documented in the child's health records.

Numerator – the number in the denominator with information on the mother's alcohol consumption in pregnancy documented in the child's health record.

Denominator – the number of births.

Data source: Local data collection, for example, local audit of child health records.

Outcome

Diagnosis rates for FASD.

Data source: Local data collection, for example, local audit 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; and systems are in

place to transfer this information after the birth to GPs and health visitors for inclusion in the child's health records.

Healthcare professionals (midwives and GPs) record information on a woman's alcohol consumption during pregnancy in her maternity records at antenatal appointments. They document the number and types of alcoholic drinks consumed, as well as the pattern and frequency of drinking. After birth, they pass this information to the GP and health visitor in transfer of care documentation so that it is recorded in the child's health records, such as maternity birth notifications, personal child health record (the 'red book') and the child's electronic care summary record.

Commissioners (such as clinical commissioning groups) commission maternity services that record alcohol use during pregnancy at antenatal appointments in the mother's maternity records and transfer this to the child's health records after the birth.

Pregnant women are asked about any alcohol they have drunk during pregnancy at antenatal appointments. The information is recorded in their maternity records and transferred to their child's health record after the birth.

Source guidance

- 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

Definitions of terms used in this quality statement

Pregnant women have information on their alcohol consumption recorded

Pregnant women are asked about the number and types of alcoholic drinks consumed, as well as the pattern and frequency of drinking at antenatal appointments. The information is recorded in maternity records. This is routine antenatal care and not part of a national screening programme such as those recommended by the UK National Screening Committee.

Quality statement 3: Referral for assessment

Quality statement

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

Rationale

Exposure to alcohol before birth can be a cause of physical, developmental or behavioural difficulties in children and young people but is often not considered when making a diagnosis. Referral for assessment may lead to different outcomes including diagnosis of fetal alcohol spectrum disorder (FASD), diagnosis of another neurodevelopmental disorder or identification of an impairment not associated with any specific diagnosis. These outcomes are important for appropriate treatment, care and support. Early diagnosis of FASD allows for early treatment and a better overall outcome. FASD is a lifelong condition; anticipating difficulties can help to avoid poor educational attainment and mental health problems.

Quality measures

Structure

a) Evidence of local pathways that allow children and young people with probable prenatal alcohol exposure to be referred to a healthcare professional with expertise in FASD.

Data source: Local data collection, for example, 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: Local data collection, for example, staff training programmes, learning resources directories.

c) Evidence of local services with healthcare professionals who have expertise in diagnosing FASD.

Data source: Local data collection, for example, service specifications, NHS trust directories of services and clinical commissioning group pathways.

Process

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

Numerator – the number in the denominator referred for assessment.

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

Data source: Local data collection, for example, local audit of patient records.

Outcome

a) Average time to diagnosis of FASD.

Data source: Local data collection, for example, local audit of patient records.

b) Diagnosis rates for FASD.

Data source: Local data collection, for example, local audit of patient records.

What the quality statement means for different audiences

Service providers (primary care services) have training for GPs to raise awareness of alcohol exposure before birth 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 with expertise in FASD and have pathways for GPs to refer children and young people for assessment.

Healthcare professionals (GPs) refer children and young people with physical, developmental or behavioural difficulties and probable alcohol exposure before birth to a healthcare professional with expertise in FASD. Before referral, they assess information about the child or young person from a range of sources, including parents, caregivers, teachers, social workers and other healthcare professionals.

Commissioners (such as clinical commissioning groups and NHS England) commission services for assessing and diagnosing FASD and develop pathways for referral of children and young people to healthcare professionals with expertise in FASD.

Children and young people with physical, developmental or behavioural difficulties who may have had exposure to alcohol before birth have a discussion with a GP and their parents about their problems. If there are concerns, and consent is given, the GP refers the child or young person for an assessment by an expert in FASD.

Source guidance

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

Definitions of terms used in this quality statement

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.

[Adapted from Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol, supporting material (information on FASD)]

Probable prenatal alcohol exposure

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

- reliable clinical observation
- self-report or reports by a reliable source
- medical records documenting positive blood alcohol concentrations, or
- alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy.

The presence of all 3 facial sentinel features (short palpebral fissures, smooth philtrum and thin upper lip) has such a high specificity for prenatal alcohol exposure and FASD 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]

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 of the possibilities when exposure to alcohol before birth is being considered as a cause of neurodevelopmental disorder. A neurodevelopmental assessment is needed for 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 being at risk of FASD) ensures the right treatment, care and support while plans for longer-term management are being made.

Quality measures

Structure

Evidence of local services with healthcare professionals with expertise in neurodevelopmental assessment.

Data source: Local data collection, for example, service specifications, NHS trust directories of services and clinical commissioning group pathways.

Process

Proportion of children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure, for whom there are clinical concerns who have a neurodevelopmental assessment.

Numerator – the number in the denominator who have a neurodevelopmental assessment.

Denominator – the number of children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure, for whom there are clinical concerns.

Data source: Local data collection, for example, local audit of patient records.

Outcome

Diagnosis rate for FASD.

Data source: Local data collection, for example, local audit of patient records.

What the quality statement means for different audiences

Service providers (such as community paediatric services, child development centres, child and adolescent mental health services) have healthcare professionals with expertise in neurodevelopmental assessments and diagnosis of FASD.

Healthcare professionals (such as community paediatricians, psychiatrists, psychologists, speech and language therapists, occupational therapists) are involved in neurodevelopmental assessment of children and young people with physical, developmental or behavioural difficulties if there are clinical concerns about prenatal alcohol exposure. The assessment covers the areas affected 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) commission services for the diagnosis of FASD that include neurodevelopmental assessments.

Children and young people who are known to have had exposure to alcohol before birth or have all 3 facial features suggesting this have a more detailed assessment if there are concerns. People from different professional backgrounds may be involved in assessing their motor skills (movement), language, cognition (thinking and reasoning) and the 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

Neurodevelopmental assessment

An assessment covering:

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

[Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol, recommendation 3.4.1 (page 19)]

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]

Three facial features associated with prenatal alcohol exposure

Short palpebral fissures, smooth philtrum and thin upper lip.

[Scottish Intercollegiate Guidelines Network guideline on children and young people exposed prenatally to alcohol, recommendation 3.1.1 (page 14)]

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 by the process for 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 after assessment as well as long-term needs. Because FASD has lifelong effects, a staged management plan may be needed to anticipate upcoming problems at planned intervals. 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 over a range of healthcare professionals, as well as education and social services, and improves outcomes.

Structure

a) Evidence of local arrangements and clinical protocols to ensure that children and young people diagnosed with FASD have a management plan.

Data source: Local data collection, for example, service protocols.

b) Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations.

Data source: Local data collection, for example, service specifications and service protocols.

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

Data source: Local data collection, for example, 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: Local data collection, for example, local audit of patient records.

Outcome

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

Data source: Local data collection, for example, a survey of people with FASD using a quality of life questionnaire.

b) Educational attainment of children and young people diagnosed with FASD.

Data source: Local data collection, for example, audit of school reports for levels of literacy and numeracy achievement.

What the quality statement means for different audiences

Service providers (such as community paediatric services, child development centres, 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, psychiatrists) develop a management plan for children and young people diagnosed with FASD. They discuss with the children and 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, including further referrals and education support.

Commissioners (such as clinical commissioning groups 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), 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 produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

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

- Time to diagnosis for people with FASD
- Experience of NHS services for people with FASD
- Health-related quality of life for people with FASD and their carers
- Educational attainment of people with FASD

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- Adult social care outcomes framework
- NHS outcomes framework
- Public health outcomes framework for 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

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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