

Reference Number: FOIAH2324/648
From: Private Individual
Date: 15 February 2024
Subject: NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder

NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder was published 16 March 2022:

<https://eu-west-1.protection.sophos.com?d=nice.org.uk&u=aHR0cHM6Ly93d3cubmljZS5vcmcudWsvZ3VpZGFuY2UvcXMyMDQ=&i=NjE1ZWVhYUwZTAZDUwZjMwZTEyMGE3&t=aWJzZHIoL2FYRy9Rd1ZhSHV4ZE42ODVnMFBOeGI3WGZuU0VxTS9uMndKYz0=&h=088da2024ecc4a04b1da31c328ca0011&s=AVNPUEhUT0NFTkNSWVBUSVbi8N15sZpOqrPInKcb1xVDHtM8Kwi3jFBsCPDk98hJYjFfa-dP5sKCGVIUVWP-acM>

- Q1 Please confirm, has this quality standard been circulated to each team and service in your network?
- A1 Quality statements 1 and 2 are not applicable to our services.
Quality Statements 3, 4 and 5 reviewed by Neurodevelopmental Paediatric Team.
- Q2 Which teams/organisations/ leads have identified that NICE Quality Standard 204 is applicable to them.
- A2 Neurodevelopmental Paediatric Team
- Q3 Please confirm if the Trust leads for a) children and young people (aged 0 to 25); b) children and young people with special educational needs and disability; c) safeguarding (all-ages); and d) learning disability and autism (all-ages) have to date included consideration of FASD and implementation of the NICE FASD Quality Standard 204 in their decision making about service provision and assessment of local need. If so, for each of the identified leads please explain how and provide any related documents.
- A3 This is currently in progress.
- Q4 If your NICE lead or other relevant person has created a review sheet, please provide that with a breakdown of every statement in the quality standard by structure, process and outcome measures.
- A4 Please see document attached - FASD-QS204 Position Statement (February 2024).
- Q5 If you don't have a review sheet, please indicate how your Trust is responding to the call for improvements in quality of care outlined in NICE Quality Standard 204.
- A5 Engaging with Integrated Care Board (ICB) for mapping of services and working with the education team to improve in house training and awareness for clinicians.

Q6 How are you involving stakeholders and/or tracking patient experiences of your response to the NICE Quality Standard 204?

A6 Involvement and engagement in mapping exercise with the ICB as part of the FASD (Fetal Alcohol Spectrum Disorder) Steering Group and liaison with the Designated Clinical Officer.

Q7 Is there any other document your Trust has created that is related to improvement of quality of care regarding NICE Quality Standard 204? If so, please provide a copy.

A7 No.

Q8 Has your ICB commissioned a pathway for FASD diagnosis?

A8 No.

Q9 Please explain the process by which someone with possible FASD would be assessed in your Trust.

A9 By referral to Neurodevelopmental Paediatrics.

QUALITY STANDARD POSITION STATEMENT

QS204 – Fetal Alcohol Spectrum Disorder

Statement	Alder Hey Response – Do we comply?	RAG	Actions needed for compliance or exception report (Evidence will be needed regardless of compliance or not – What evidence do you have?)
Statement 1	Not applicable – relates to antenatal care and advice.		
Statement 2	Not applicable – relates to antenatal care		
Statement 3	<p><i>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.</i></p> <p>Children are currently referred to the service. All developmental paediatric consultants accept referrals for FASD. It should be noted this is not a pathway, but the developmental paediatric team do assess for FASD as part of the standard assessment.</p> <p><i>b) Evidence of local arrangements to increase awareness of FASD among healthcare professionals.</i></p>		<p>Internal referrals</p> <p>All children being assessed or diagnosed for FASD should be coded on trust electronic systems.- to be discussed</p> <p>There should be a training package for FASD for new registrars but available to the rest of the trust - to be developed. This work is being picked up via C&M Beyond Programme.</p> <p>There should be a presentation regarding the SIGN and NICE guidelines in Grand Round which is hospital wide teaching- completed.</p> <p>External referrals</p> <p>Once there is a dedicated service, this will be communicated with social care, primary care and education.</p>

There have been regional study days and one of the conferences on looked after children hosted by Alder Hey included sessions regarding FASD. There is no formal training to outside agencies provided by Alder Hey for FASD.

Training for FASD is incorporated in the induction talk for looked after children given to every new registrar and staff grade.

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

There is no clearly defined service, however assessment is part of the community paediatric remit. There are variable levels of training, knowledge, understanding and skill in being able to assess for FASD which has resulted in some complaints; one complaint stated the clinician seeing the child explained there was no one with expertise in assessing FASD.

Another example of variability was a child diagnosed in New into Care clinic as he was dysmorphic, had learning difficulties in a special school with an EHCP and mum stated she drank a bottle of vodka a day during pregnancy. This child had been under the Developmental

External referrals - there is no dedicated service for FASD assessment yet as this has not been funded- we are involved with the mapping exercise and workshops the ICB has organised as part of the Beyond FASD steering group - this will help to provide direction on how a service could be delivered moving forwards and how this may be resourced as it requires a dedicated multidisciplinary process.

Liaison with ICB designated nurse and doctor for Looked After Children regarding training for FASD awareness across agencies to support better communication

	Paediatric service for a number of years.		
<p>Statement 4</p>	<p><i>Evidence of local services with healthcare professionals with expertise in neurodevelopmental assessment who have had additional training in FASD.</i></p> <p>There is no pathway for referral outside of a standard referral to the developmental paediatric department.</p> <p>Some clinicians have done additional training through the RCPCH, NOFAS-UK and study days. There were 3 consecutive weeks in departmental medical teaching in 2020 around FASD.</p> <p>A number of staff have attended or completed online FASD courses.</p> <p>Training for FASD is incorporated in the induction talk for looked after children given to every new registrar and staff grade.</p>		<p><i>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.</i></p> <p>There should be a training/awareness package for FASD for new registrars but available to the rest of the trust.</p> <p>There will be development of a management document on EPR for the possibility of bringing evidence together for FASD based on SIGN guidance. The trust is moving to a new EPR and development of the management document will occur after this.-</p> <p>-currently on hold until clarity on service provision</p> <p>Trust guideline for the assessment of FASD-</p> <p>One of the gaps within the service is access to a psychologist within the neurodevelopmental team and a business case will be submitted to aid the assessment process.</p> <p>Ideally there needs to be the development of a unifying streamlined service looking at all areas for FASD.</p>

Diagnosis rate for FASD

There is an audit currently underway for comorbid conditions such as ASD and FASD in the ADHD population.

This is currently on hold until mapping exercise is completed and resource provision is agreed

This could be linked closely to the looked after and post adoption children as it is estimated around 30% (60% in some studies) of the looked after population may have been affected by antenatal alcohol exposure.

The assessment process requires expertise in neurodevelopmental difficulties, speech and language, psychology and OT to be able to fully assess the 9 areas of concern. It is also noted to rule out other concerns, a diagnostic assessment has to include attachment/trauma/neglect although it is accepted these conditions can and often do coexist.

It should be noted the proposed service would also comply with [NICE quality standard 5](#) from the guidance for looked after children and young people.

Children who are being assessed or who have been diagnosed for FASD should have this coded on EPR. Diagnosis rate can then be assessed based on population data and numbers diagnosed.

<p>Statement 5</p>	<p><i>a) Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations.</i></p> <p>In a survey of consultants who assess for FASD there was a large amount of variability in being able to coordinate services with only two respondents stating it was a team diagnosis and 67% stating they use the SIGN guidance. 57% stated they were unable to coordinate care and assessments across disciplines.</p> <p><i>b) Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services.</i></p> <p>Only one respondent to the survey stated the child had received a SMART plan.</p> <p>All letters are copied to school, school nurses and social worker if involved. IHA's are available on the EPR and there are standard comments regarding the risk of FASD in the Looked After population. Social worker details are on the EPR and Medisec for Looked After Children. The social worker details</p>		<p>Awareness of FASD via liaison with ICB Designated Doctors and Nurses for Looked After Children regarding training for outside agencies.</p> <p>Training regarding "Care Aims" reports to improve plans for children.</p>

	for in area children are kept up to date on EPR.		
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