

## Fetal Alcohol Spectrum Disorder (FASD)

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Reference Number: RDF2341-24

Date of Response: 26/03/24

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

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

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204&data=05%7C02%7Crduh.foi%40nhs.net%7C10e850b62a11452c91b308dc2e44c299%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638436120055587661%7CUnknown%7CTWFpbGZsb3d8eyJWljojMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=dCB5aB5w26kSAIXPUVLo9QJlvj%2B9LzHRmDYuA0diacU%3D&reserved=0>  
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1. Please confirm, has this quality standard been circulated to each team and service in your network?.

Answers: Trust wide Paediatrics:

Yes. Multiple members of the community Paediatric team have attended the Royal College of Paediatrics and Child Health Fetal Alcohol Spectrum Disorder course within the last few years – this course covers the updated SIGN guideline and recommendations in detail. The information within the guideline and quality stands was presented to the Community Paediatric team at a departmental CPD session on the 1<sup>st</sup> September 2023 and at the Children in Care South West Network meeting in November 2023. An updated guideline is currently in draft form and will be reviewed by the Community Paediatric team at the upcoming team clinical effectiveness meeting.

2. Which teams/organisations/ leads have identified that NICE Quality Standard 204 is applicable to them.

Answers Trust wide Paediatrics:

Community Paediatrics and Neurodisability team (including the Children in Care team)

Please note that quality standards 1-3 are also applicable to other teams including primary care (health visitors, school nurses, GPs).

3. Please confirm if the Trust leads for

a) children and young people (aged 0 to 25); Paediatrics answer: Not known

b) children and young people with special educational needs and disability; Eastern Paediatrics answer: Yes, please see above. Part of the community paediatric team

c) safeguarding (all-ages) Eastern Paediatrics answer: Children in Care team – yes. Please see above.

d) learning disability and autism (all-ages)

Answers Trust wide Paediatrics: Yes – please see above. Part of the community paediatric team

4. 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.

Answers Paediatrics: Not applicable.

5. 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.

Answers: Trust wide Paediatrics:

FASD Trust guideline being updated to include the SIGN 156 guidance and NICE 204 standards. Once finalised, this will also be shared with the general paediatric team and safeguarding teams.

Audit planned for 2024: retrospective review of notes to demonstrate evidence that a diagnosis of FASD has been considered with every neurodevelopmental assessment undertaken:

- History of alcohol intake during pregnancy.
- Measurement of height, weight, and head circumference.
- Consideration of facial features and other dysmorphism made and recorded.
- Assessment of areas neurodevelopmental impairment (through history and onward referral where appropriate)
- Management plan put in place to address needs.

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

Answers Trust wide Paediatrics:

We have not involved stakeholders or patient tracking experiences specifically for FASD but have used data from the patient carer forum to inform our wider neurodevelopmental assessment pathway.

7. 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.

Answers Trust wide Paediatrics:

Updated guidance currently is currently in draft form. It is based on the SIGN 156 guidance and Royal College of Paediatrics course on Fetal Alcohol Spectrum Disorder.

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8. Has your ICB commissioned a pathway for FASD diagnosis?

Answers Trust wide Paediatrics:

Not that we are aware of. We incorporate this into our existing neurodevelopmental assessment pathway.

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

Answers Trust wide Paediatrics:

The Community Paediatric team accept referrals from a variety of different professionals including GPs, School Nurses, Health Visitors, General Paediatricians, CAMHS, social workers (for children in care). The referral would be triaged to an appropriate clinic which for someone with possible FASD would likely be a neurodevelopmental assessment clinic. The lead clinician would complete a clinical interview with the young person and their parents(s)/carer(s) which would include a history of prenatal alcohol exposure and developmental history to understand which neurodevelopmental areas may be impaired. A physical examination including head circumference measurement and presence, or absence of facial features associated with FASD would be completed. If there was concern about possible FASD following this initial assessment, further evidence of neurodevelopmental impairment would be collected from existing assessments or by referral to appropriate specialists. Genetic testing would be considered. The young person would then be seen again in clinic to feedback about the assessment -whether the young person meets criteria for FASD with or without sentinel facial features/does not meet criteria for a diagnosis/remains at risk for a diagnosis of FASD.

