

Our Reference North East and North Cumbria
ICB\FOI ICB744

NECS – John Snow House
Durham University Science Park
Durham
DH1 3YG

Tel: 0191 301 1300

E-mail: necsu.icbfoi@nhs.net

Applicant
By Email

28 February 2024

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received by North of England Commissioning Support (NECS) on 31 January 2024 for information held by NHS North East and North Cumbria Integrated Care Board (NENC ICB) under the provisions of the Freedom of Information Act 2000.

NENC ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the 5 councils that make it up – Darlington, Hartlepool, Middlesbrough, Redcar & Cleveland, and Stockton-on-Tees).

Your Request and Our Response

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%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772366111%7CUnknwn%7CTWfPbGZsb3d8eyJWljoimC4wLjAwMDAiLCJQljoiv2luMzliLCJBTil6lk1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=0PD9ISO6ela7Q0Dlwx4Qcf84hHnO0tsjFZiqMhTBQrc%3D&reserved=0>)

1. Please confirm, has this quality standard been circulated to each team and service in your network?

NICE QS204 was circulated to all NENC Maternity Services, through the NENC ICS Alcohol Clinical Network and to non-ICS networks ADPH CYP Commissioners Forum and 0-19 Service Leads on 17th March 2022.

2. Have teams or other organisations within your ICB been asked to identify whether NICE Quality Standard 204 is applicable to their service?

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

For Q2 and 3, the ICB are currently reviewing structures and processes in relation to clinical effectiveness, this will include an ongoing review of NICE guidance implementation. This specific standard will be included in future workplans for review of compliance.

4. Please confirm if the lead ICB board members 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.

For CYP, learning disabilities and SEND there is a mixed offer across the ICB footprint due to previous developed CCG level pathways and in relation to a diagnostic pathway which potentially inhibits to a certain extent the wider preventative work that can be undertaken. We have a diagnostic pathway within NTEES, CNTW, Sunderland and emerging in STEES, once embedded we will look to consider how this becomes a part of the Neurodevelopmental pathway. There is an ICB wide group that is led by CYP commissioners sharing best practice and mapping and exploring how a diagnostic pathway can be implemented across all places to ensure equity across the ICB.

Across the Tees Valley FASD was identified as a joint priority area between the ICB and all Directors of Children Services, a task and finish group identified a program of work to take forward which includes prevention, education, diagnostics and the voice of parents/carers and CYP with a diagnosis- the wider work will progress following the implementation of the diagnostic pathway in Stees. There is a commissioned family support service accessible for CYP and families with a neurodiverse presentation which includes FASD- this is available irrespective of a diagnosis it is a needs led service .

5. Please indicate who in your ICB has responsibility for each NICE Quality Standard 204 statement:

5a. Statement 1: Advice on avoiding alcohol in pregnancy (Pregnant women are given advice throughout pregnancy not to drink alcohol.)

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-1-Advice-on-avoiding-alcohol-in-pregnancy&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772373478%7CUnknown%7CTWFpbGZsb3d8eyJWljiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6IjEhaWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=3hMBNyaHljacZ2SCDtXkNtKIRg6VZazlPe2xoKZOdHM%3D&reserved=0>

The responsibility to provide advice on avoiding alcohol in pregnancy contained within NICE QS204 is jointly held between all registered practitioners (majority Midwifery staff), led by each of the NHS Trust Directors/Heads of Midwifery and overseen by the LMNS.

5b. Statement 2: Fetal alcohol exposure (Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded)

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-2-Fetal-alcohol-exposure&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772373478%7CUnknown%7CTWFpbGZsb3d8eyJWljiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6IjEhaWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=3hMBNyaHljacZ2SCDtXkNtKIRg6VZazlPe2xoKZOdHM%3D&reserved=0>

[3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772378882%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=uwR11AEavIWGa3l6noU4nq1gdltPu9aFDZu2QcPOIW8%3D&reserved=0](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-3-Referral-for-assessment&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772378882%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=uwR11AEavIWGa3l6noU4nq1gdltPu9aFDZu2QcPOIW8%3D&reserved=0)

All NENC staff have access to high quality training and an adapted AUDIT C tool to support assessment during pregnancy. This is currently undertaken at the first booking, 16 weeks and 36 weeks gestation as a minimum in line with the NENC pathway. Data quality improvement work is currently being undertaken.

5c. Statement 3: Referral for assessment (Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.)

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-3-Referral-for-assessment&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772383076%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=8LA9XKwt26P8a%2BsjVFe7yED%2FoEfr1QzkoyT27Dm9YnU%3D&reserved=0>

Depending upon the presentation and age of the child they would either be referred to community paediatrics, Neurodevelopmental pathways or CAMHS for an assessment.

5d. Statement 4: Neurodevelopmental assessment (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.)

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-4-Neurodevelopmental-assessment&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772387162%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=DOFBeCbHCreeG%2FpEIWJuO7nSqPWGfLa5UdgD8zhQumc%3D&reserved=0>

See question 4 a specific assessment for FASD will vary across trusts however all CYP will be assessed to determine clinical need and required intervention.

5e. 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.)

<https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Fqs204%2Fchapter%2FQuality-statement-5-Management-plan&data=05%7C02%7Cnecsu.ICBfoi%40nhs.net%7C6d95c7014c514584ee7008dc2262fe3a%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638423055772391278%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTiI6Ikk1haWwiLCJXVCi6Mn0%3D%7C0%7C%7C%7C&sdata=DXswhN4ly6ke%2FqfiOv20j5S0V%2B%2B0x3VgTESq0bu5n8U%3D&reserved=0>

CYP with a diagnosis of FASD will have a management plan but as above in 4 this may vary across trusts/places.

6. 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.

7. If you don't have a review sheet, please indicate how your ICB is responding to NICE Quality Standard 204.

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

For Q6, 7 and 8, the ICB are currently reviewing structures and processes in relation to clinical effectiveness, this will include an ongoing review of NICE guidance implementation. This specific standard will be included in future workplans for review of compliance.

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

Please find attached, copies of relevant documents.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right to complain to the Information Commissioner as established by s.50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

www.ico.org.uk

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector

Information Regulations 2015 www.legislation.gov.uk . This will not affect your initial information request.

Yours sincerely

H Murphy

Hilary Murphy
Information Governance Officer