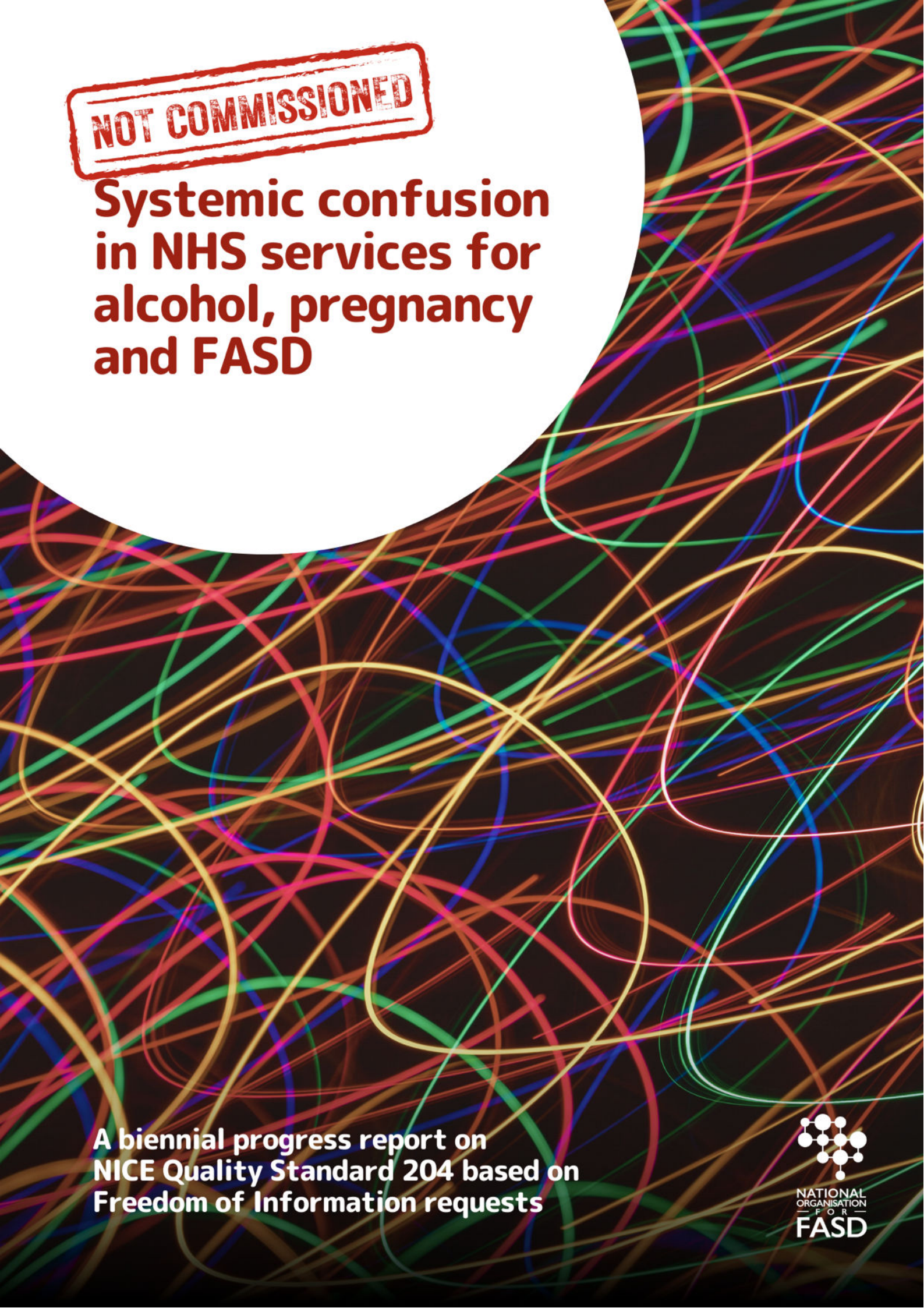


Systemic confusion in NHS services for alcohol, pregnancy and FASD

A biennial progress report on NICE Quality Standard 204 based on Freedom of Information requests

NATIONAL ORGANISATION FOR FASD

The National FASD Biennial Progress Report

September 2024

The National Organisation for FASD

NOT COMMISSIONED: SYSTEMIC CONFUSION IN NHS SERVICES FOR ALCOHOL, PREGNANCY, & FASD

SUMMARY

1. **New research from The National Organisation for FASD shows the majority of NHS Integrated Care Boards and NHS Trusts are missing a golden opportunity to protect baby's brains and futures with their slow, non-strategic and uncoordinated responses to a landmark document, the 2022 NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder (FASD)**, which called for improvements in care regarding discussions about risks of alcohol in pregnancy during antenatal visits and recognition, assessment, diagnosis and support of those with FASD.

2. **Fetal Alcohol Spectrum Disorder is a *preventable* neurodevelopmental condition with lifelong cognitive, emotional and behavioural challenges. In recent years, all major national public health bodies have recognised the importance of FASD prevention, diagnosis and support.**

3. It is now understood that with a conservative prevalence rate of 2-4% there are more people with FASD than autism[1] and most other neurodevelopmental conditions, however FASD continues to have less public profile, services, provision and funding. Getting this right could help relieve financial pressures on overstrained services across health and social care, as there are people with diagnosed and undiagnosed FASD are already within the services but not being appropriately supported.

4. National public health bodies have stated FASD requires intervention. In particular, after the 2019 SIGN 156 diagnostic guideline for children and young people prenatally exposed to alcohol (accepted by NICE and in place across Scotland, England and Wales) and the 2021 DHSC FASD Health Needs Assessment for England, NICE recognised the need for improvement in services by issuing in 2022 NICE Quality Standard 204. NICE QS 204 has 5 statements, each outlining steps to improve quality of care on 1) advice on avoiding alcohol in pregnancy, 2) fetal alcohol exposure, 3) referral for assessment, 4) neurodevelopmental assessment and 5) management plan.

FINDINGS

5. **This report shows that in the two years since NICE Quality Standard 204, Boards and Trusts have not responded with the urgency that is required.**

6. **National FASD sent Freedom of Information requests to all Integrated Care Boards (42) in England, all Welsh Health Boards (7) and 211 of 215 NHS Trusts in England and Wales** available via the What Do They Know portal. By law, public bodies have 20 working days to reply. This report collates the responses received from 36 ICBs, 5 health boards and 105 Trusts by the statutory deadline. (We have excluded 11 specialist ambulance trusts from our figures though we believe they need FASD training too). The number and variety of responses received are enough to provide an overall picture of the national response to NICE QS 204. (The report includes links to responses that arrived after the deadline.)

7. **Responses received show that while there are pockets of hope and encouraging**

[1] According to a gold-standard active case ascertainment study done by the University of Salford, 1.8 – 3.6% have FASD. (McCarthy et al., 2021. https://pubmed.ncbi.nlm.nih.gov/34590329/). The WHO estimates 1% have ASD. (WHO, 2023. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders)

progress, more broadly there is systemic confusion and a lack of coordination. The report features progress in a few key localities, including Greater Manchester, Sheffield and Hackney where policy makers and leaders from different sectors have responded creatively to NICE Quality Standard 204 and have embedded NICE QS 204 into key planning documents, raised it within relevant boards, conducted training, local scoping exercises and audits or more. They and other bodies across the country who have responded to NICE QS 204 stand are examples that other ICBs can learn from, especially those who flat out deny there is a role for their ICB to take action. In addition, we highlight some areas taking action on creative commissioning like Kent and Medway or in their approach to engaging stakeholders and making material accessible – for example Oxford Health NHS Foundation Trust and Central and North West London. Alder Hey's Children's NHS Trust and South Tyneside and Sunderland are taking positive action using NICE QS 204 indicators.

8. This is critical because where there has been inaction women, families and children are left without life-changing information and support. Even in areas where there has been progress, it is just the beginning of the needed systemic changes and ongoing monitoring of improvements in quality of care.

9. **Responses were rated on a RAG system (red, amber, green).** Red indicates that the body did not demonstrate it is taking action on NICE QS 204. This could include some Trusts who consider themselves 'compliant' but who are not implementing any changes or do not seem to be using the indicators provided by NICE QS 204 to track improvements. Amber responses indicated some action, but they might not have considered all 5 statements in the NICE QS. Green responses demonstrated some sort of systemic and ongoing action, typically across the 5 statements. We recognise the limitations of judging solely on the responses received as opposed to checking this against patient experiences and other measures. **For this first report on the national response to NICE QS 204, we are being generous. Any sign of action, task and finish groups, efforts to review policies, discussion of training, attempts to track indicators, etc all were accepted at face value and welcomed as initial steps toward improvement in quality of care.**

10. **Responses indicate that nearly 53% of ICBs and 56% of NHS Trusts (not including the 11 specialist ambulance trusts) that replied to National FASD's Freedom of Information requests are not taking action to meet the needs of this vulnerable population and to prevent alcohol-exposed pregnancies. In Wales all the health boards that responded are taking at least partial action** (but we note that given the smaller numbers the lack of response from 2 of the 7 Boards might be skewing that perception of progress).

11. **In addition, the vast majority of English Integrated Care Boards who replied by the deadline are not commissioning for diagnosis and management of care for children (70%), young people (73%), and adults (87%) and the majority of Welsh Health Boards have not commissioned services for diagnosis and management of people for children (67%), young people (67%) and adults (83%).**

12. **The majority of health policy makers across England and Wales are failing to take action, many claiming it is not their responsibility. The majority of NHS Trusts are failing to implement the national standards to improve services relating to alcohol in pregnancy and FASD and commissioners are failing to commission for FASD.**

13. **One of the major findings is that there are unclear lines of responsibility between ICBs/ Health Boards and Trusts, as well as within Trusts between different services**. We are reminded of the game 'hot potato' where something is considered too hot to handle and is quickly passed to someone else. While FASD prevention, diagnosis and support has been determined by the country's leading public health bodies (DHSC, NICE, SIGN, PHE/OHID) to be a

burning issue, in most cases the relevant parties are handing off responsibility to others while in the meantime people with FASD, their families, and pregnant women are being failed by a system meant to protect them. The report includes examples of this.

a. For example in Birmingham the ICS states that "no formal FASD service is commissioned" and encourages National FASD to "please contact the trusts directly." The ICB says that in 2024/25 the Community Paediatric services will consider FASD requirements. However, one of the related trusts, Birmingham Community Healthcare NHS Foundation Trust said, "Some diagnoses are given by the community paediatrician however this is challenging due to the lack of a defined pathway and the evidence required from multi-disciplinary team. Children with concerns about possible ADHD/ASD would be referred directly to the ADHD/ASD pathway. FASD may be considered as part of the presentation and assessment however it is not an assessment pathway for FASD specifically and *a diagnosis would not be given during this assessment*. If there are concerns which might suggest this children can then be referred to community paediatrics for assessment but these would only be seen if fulfilling the remit of our current referral criteria for Community Paediatrics and wouldn't necessarily be seen for FASD assessment specifically if there are no developmental concerns as part of this." [Emphasis added] In other words, the Trust is not doing an FASD assessment because there is not a clearly commissioned pathway. It is unclear if the ICB will address this problem or simply add FASD to the end of exciting ASD/ADHD pathways without needed training for professionals to be able to give FASD diagnoses.

b. Similarly, in South Yorkshire the ICB states, "Currently there are no specific services commissioned by NHS South Yorkshire ICB for the diagnosis and management of people with FASD for any age group. We would expect this condition to be picked up through paediatric pathways where the presentation would be related to developmental/ neurodevelopmental delay, and would potentially include genetic testing for other diagnoses etc." However, Barnsley Hospital NHS Trust (which has community paediatric services) says, "We do not [have] a pathway or resource for FASD. ICB has not commissioned a pathway for FASD in Barnsley. We do not have a process or the right professionals to assess FASD."

c. NHS Bristol, North Somerset and South Gloucestershire ICB states, "The current structure and ways of working in BNSSG ICB means that commissioned providers are responsible for responding to NICE quality standards. BNSSG ICB as an individual organisation is not responding directly to this quality standard." However, University Hospitals Bristol and Weston NHS Foundation Trust for example say: "The Trust is not commissioned to provide FASD services."

14. Questions remain even for those areas that claimed in their responses to be compliant with NICE QS 204.

a. Many claimed to be compliant with Statements 1 and 2 on advice during pregnancy and recording of alcohol-exposed pregnancies. The feedback in almost all responses does not give information about whether it is only maternity services that are doing this or other healthcare professionals within the trust that come into contact with pregnant women, which could be missed opportunities for prevention. Whilst some areas state that they have guidelines in place to meet statement 1 of NICE QS204, they have not all evidenced what specific information is given and whether this is both written and verbal. It isn't clear whether all healthcare professionals have had specialist training on the risks associated with an alcohol exposed pregnancy and FASD awareness and alcohol brief interventions. Where staff have not had the training there may be significant differences in the information given by healthcare professionals which could put some pregnancies at risk. A recent national poll conducted by OnePoll for National FASD showed that 20% of adults still do not recognise the CMOs guidance nearly 8 years

after the guidance changed. Nor did, alarmingly, 34% of adults aged 25-34 (key childbearing years). In London, 33% of adults did not recognise the guideline. Some responses say alcohol asked about and recorded. However, it is unclear what is being recorded. Where digital health records do not require questions about alcohol to be mandatory, they could be missed. It is not clear that all women are being asked throughout pregnancy.

b. Indicators should be used to measure progress. **There is a nearly universal failure to use NICE indicators for tracking improvements in services over time. No ICB or Trust can claim to be fully compliant with the Quality Standard if they are not also tracking over time the provided demonstrable indicators** to show they are improving their services to meet the need. Using a NICE Quality Standard is meant to be a dynamic exercise and only a very few bodies are using these indicators.

c. **Training reviews are needed before claiming compliance**. ICBs and Trusts cannot rely on being compliant with NICE QS 204 without additional training in FASD. Those who have said they are 'compliant' should review what training their staff has had and begin tracking their progress via the indicators suggested in NICE QS 204.

15. **Local pathways are unclear and under resourced. Many responses indicate that local diagnosis is not available**.

a. **The first steps toward increasing local capacity is recognising the strength of what resources are available locally.** The *Time is Now* report[2] has best practice and practical ideas for those areas thinking about this issue. It was created with input from more that 60 practitioners, experts, commissioners and people with lived experience. It has whole sections on how to ramp up local diagnostic services, to explore the difference between multidisciplinary teams and multi-disciplinary assessment and to show the range of tests, many of which are available to local services, that can contribute to FASD diagnosis. In all areas of the country there are practitioners using tests on a daily basis that could inform an FASD assessment and therefore with co-ordination, but very little additional expenditure it could / should be possible to make meaningful assessments of FASD.

b. **Many ICBs have talked about including FASD as a possible diagnosis in their neurodevelopmental pathways, but few have recognised the need to increase commissioned resources to allow for the extensive ND assessments needed to complete the FASD diagnostic assessment. Nor have they looked at proactively commissioning FASD support resources for when these children and young people are diagnosed.** For those areas that rely solely on sending cases to the national clinic, because of the prevalence they should really have local provision for diagnosis with recourse to a national resource if they are unsure of the diagnosis – the Hub and Spoke model. The Surrey and Borders Partnership NHS Trust is home to the FASD National Service in Surrey. This clinic, led by Prof Raja Mukherjee MBE has been helping to support other areas as they develop local services.

16. Statutory guidance on executive lead roles within ICBs states that each ICB should have lead members of the board with explicit responsibility for children and young people (aged 0 to 25), children and young people with special educational needs and disability, safeguarding (all-ages); and learning disability and autism (all-ages). These leads are expected to make decisions around service provision relating to these population groups based on assessment of need in the area. This should include consideration of FASD and implementation of the NICE FASD Quality Standard. It appears from responses that **there is confusion among ICBs whether their leads as identified above are taking NICE QS 204 into account in their duties to improve**

[2] The Time is Now, National FASD (2022) - https://nationalfasd.org.uk/the-time-is-now-ramping-up-fasd-support-services/?utm_source=rss&utm_medium=rss&utm_campaign=the-time-is-now-ramping-up-fasd-support-services

quality of care. Responses were very varied as to who was leading on NICE QS 204. Over a third said they didn't have a lead or that they had no data. Others said that it was up to the trusts or individual providers. Several only suggested leads in maternity or neonatal services, which does not take account statements 3-5.

17. While it is beyond the scope of this report to supplement the claims made by ICBs, Health Boards and Trusts with the lived experience of stakeholders in each of the areas, **we offer 14 case studies to shed more light on why even highly specialised Trusts should be taking action on NICE QS 204 and why the training called for in NICE QS 204 is urgently needed.** These case studies are the tip of the iceberg. Every person with FASD and every family will have similar examples of the lack of training, pathways and informed support. Examples of the case studies include:

    a. For example, one birth mum whose child was misunderstood by ophthalmology services and whose eye was at risk as a result stated, "D's experiences over his journey with FASD have been a mixture of positive and negative. The positive experiences have always related to professionals who know about FASD and accept him for who he is. Who understand his needs and meet them. His negative experiences, many many negative experiences, have always been with professionals who don't know about FASD and who refuse to read up or educate themselves about it. For me personally, these experiences have been incredibly frustrating and belittling."

    b. Another mum described her daughter's atypical seizure presentation and the failure of neurology services to understand FASD, saying, we "still have no real answers or treatment, and have not seen a neurologist who can help manage her care, who can help her understand how this unusual presentation might link to her FASD and what the impact might be as she grows older."

    c. A pregnant woman stated she is "a pregnant woman who only discovered my pregnancy at 16 weeks. Fortunately, I do not consume alcohol, so my baby is not at risk of Fetal Alcohol Spectrum Disorder (FASD). However, I find it bewildering that, despite being 32 weeks along and attending several midwife appointments, I have not been asked about my alcohol consumption prior to knowing I was pregnant."

18. **The report includes extensive Appendices including the questions asked of ICBs, Health Boards and Trusts and the actual responses received.**

    a. **We have included the full responses (though not any additional material provided) to help spur creative thinking from leaders in different areas to see what others are doing (or not doing) in response to NICE QS 204**.

    b. Please note, we have put a "response" hyperlink by every entry. Readers accessing the PDF version of this report on screen can use these links to see the actual correspondence and responses (including added material, charts, etc). Even if the ICB, Health Board or Trust did not respond in time for this report preparation, do look, as their response might have come through and will be accessible via the link provided.

    c. We have included the responses received from the 11 specialist ambulance trusts in the appendices but we have not included their replies in our figures. While we believe ambulance trusts should have FASD training we accept they are not likely to be involved in management plans. However, other specialist trusts may be called upon to be involved in management plans and we have included them for that reason.

ACTIONS NEEDED

19. Decreasing the incidence of FASD (permanent damage to developing brains and bodies) and ensuring those who have FASD have diagnosis and support should be everyone's business.

20. Without addressing this 'hidden epidemic' efforts to improve mental health, wellbeing

and to improve services for people with autism, learning disability and ADHD will remain stymied.

21. **National FASD calls for strong leadership from Parliament, Government and national health bodies to operationalise the policy. We call for**:

a. **A Green Paper based on the DHSC FASD Health Needs Assessment and NICE QS 204**, examining how recommendations can be implemented and overseen on a national level, leading to a White Paper and an FASD Prevention and Response Act.

b. **A Welsh Government Green paper on FASD Prevention and Response**, focusing on NICE QS 204 and implementation of SIGN 156.

c. **Establishment of an FASD Prevention and Response Fund equivalent at least to 0.1 – 0.2% of the alcohol duty** to put UK spending in this area on par with other countries.

d. **Support from NHS England for an ongoing audit of progress following NICE Quality Standard 204**, including lived experience.

e. **ICBs should be given clear guidance by NHS England that they are expected to commission services to support FASD with similar strong guidance from NHS Wales to Health Boards in Wales**.

f. **Each ICB and Health Board should appoint an FASD lead and have in place an area-wide ability to check what the Trusts are doing to track over time improvements in quality of care as called for in NICE QS 204**. Tracking NICE Quality Standard 204 indicators should be mandatory.

g. **Recently introduced SNOMED CT codes for FASD should be promoted by the Chief Medical Officers** and others to ensure FASD can be tracked through routine electronic patient records and included in a future national FASD database.

h. Similarly, **the digital health records for maternity services need to be updated to include mandatory and consistent coding and prompts for discussing and recording dose, pattern and timing of alcohol-exposed pregnancies**.

i. In response to NICE QS 204 Statements 1-2, National FASD calls for **greater efforts nationally, regionally and locally to raise awareness of the risks of alcohol in pregnancy at least on scale with smoking in pregnancy public health campaigns, including posters and banners about the risk of prenatal alcohol exposure in maternity waiting areas and adverts about alcohol-free pregnancies in NHS social media channels** and in which NICE QS 204 recommendations are followed that women are given information about prevention of further harm if PAE stopped and referrals to appropriate service/ specialist midwife.

j. With regards to NICE QS 204 Statements 3 and 4 **steps needs to be taken to increase local and regional diagnostic capacity including FASD training, staffing and commissioning for diagnostic pathways either via paediatric or neurodevelopmental services. Special attention should be given to training, hiring and licensing of clinical psychologists and other professionals to conduct the neurodevelopmental assessments called for in NICE QS 204. Funding should be made available to implement the DHSC FASD Health Needs Assessment recommendation for a Hub and Spoke working model**, including support for the national FASD clinic in Surrey, on a spend-to-save basis to help jump-start services.

k. NICE QS 204 Statement 5 calls for management plans for people with FASD but this report demonstrates this is not happening. **Each area needs to have a plan in place for post-diagnostic support, preferably an FASD pathway. Every management plan should have a named lead on the plan. The FASD UK Alliance draft model management plan could be used.**

l. **Any programme for those with Autism and Learning Disability should be extended to include FASD and their staff should have mandatory FASD training and make appropriate adjustment to their offer to**

include FASD strategies. Moving forward any NHS programme for people with neurodevelopmental conditions must take into account SIGN 156, the DHSC FASD Health Needs Assessment and NICE QS 204.

m. Mandatory FASD training including details about the risks of alcohol in pregnancy, the importance of motivational interviewing strategies and alcohol brief interventions, the importance of diagnosis and FASD-informed support is called for in all recent policy statements (SIGN 156, DHSC FASD Health Needs Assessment and NICE QS 204). Responses to National FASD's Freedom of Information requests clearly demonstrate a lack of emphasis on FASD-specific training at all levels. As such this report clearly highlights the **need for national level guidance, oversight and funding for FASD training across health and social care sectors.** The report highlights training available from National FASD, Royal College of Paediatrics and Child Health, the Fetal Alcohol Advisory Support Training Team/ University of Edinburgh, and FASD UK Alliance groups all provide training. It was noted the Royal College of Psychiatrists also have a report in development about FASD.

FOREWORD - SANDRA BUTCHER

Chief Executive, National FASD

It's not often that we are able to have a front-line seat on a national health revolution. For those of us working in the FASD field, that is exactly what the last few years have felt like. Finally, 50 years after the first FASD diagnosis, the UK policy apparatus – all national public health bodies - have woken up to the reality that there are more people walking through our streets who experienced lifelong alcohol harm before they drew their first breath than have autism, and that with proper diagnosis and support for FASD (Fetal Alcohol Spectrum Disorder) their trajectories can be positive and productive. It's recognised now that with proper training we can support the workforce to ensure that we limit future cases of FASD through prevention.

This report is about how England and Wales now have an unprecedented opportunity to implement improvements in the quality of their services by seriously reviewing and operationalising NICE Quality Standard 204 on FASD, issued two years ago. It's about how action is needed from on high to ensure this opportunity is not missed in a complicated political and health and social care landscape.

I was honoured to be a lay person on the committee that led to NICE QS 204 along with another parent of young people with FASD. After the years of delay in the release of the Quality Standard, once it was published she and I spoke. We knew it was coming, but seeing it finalised left us stunned a bit. We were emotional. Gobsmacked. Parents used to fighting for our loved ones in a world that didn't even acknowledge our amazing children have lifelong brain damage, let alone that they need – and deserve – support to help them live their best lives, we knew deep down that something transformative had happened. Never in our wildest dreams had we expected something so strong to come out of the process.

NICE QS 204 covers advice and recording of alcohol use in pregnancy, assessment for those at risk and emphasises the importance of a neurodevelopmental assessment and importantly a proper management plan for those with FASD for their lifelong needs.

Two years later, there is change happening. This report shows there are a few pockets of brilliance across the country and definite signs of hope.

And yet, by far the reality is that ICBs and NHS Trusts are not tracking over time the indicators provided by the NICE QS to ensure they are actually improving services (this is the point of a NICE QS, it's not a one-off tick box exercise). By far, most services and commissioners don't consider FASD prevention, recognition and support to be their responsibility. By far, the need for training that runs throughout the NICE QS has been ignored. Sadly, funds are continuing to be wasted by not ensuring proper pathways and appropriate assessments.

> **Think about the massive change operationalising NICE QS 204 can have on the health of the nation, on the lives of some of our most vulnerable.**
>
> **-Sandra Butcher**

Tragically there are people with FASD and their families in crisis, still banging their heads against systems that refuse to budge while each precious opportunity to help them is missed

because this issue still has not been given the priority it deserves. When we ask about management plans you can almost hear the crickets chirp.

We believe this can change. We encourage all reading this report to join the revolution. Think creatively. Join forces with like-minded individuals. Open up the funding streams. Think about the massive change operationalising NICE QS 204 can have on the health of the nation, on the lives of some of our most vulnerable. Let's roll up sleeves and get this done. National FASD stands ready to help.

(Note: Sandy served as member of the NICE QS 204 committee but is writing this in her personal capacity.)

FOREWORD - DR PATRICIA JACKSON OBE FRCPCH

Co-Chair SIGN 156, Trustee, National FASD,
Paediatrician, Honorary Fellow University of Edinburgh Department of Child Life and Health

When any Guidelines and Quality Standards are published, their importance is in the way they influence the health care of those with the condition, in this case those living with FASD and those who support them.

This important review by National FASD details the progress that is being made across a sample of ICBs, Health Boards and Trusts that replied to Freedom of Information requests.

It is disappointing to see that despite the NICE Quality Standards being published over 2 years ago many areas have not yet acknowledged the need for a clear implementation plan to improve service to those individuals with this common condition.

On the positive side there are a few great examples of effective implementation which could act as a model.

It is encouraging to see that healthcare professionals are seeing the need for training and provision of multiagency assessment and support services, but a major block appears to be in the commissioning and funding of these developments, a requirement clearly recognised in the publication of the NICE Quality Standard.

Hopefully this publication will be the first of a regular review process to document improving services to individuals affected by FASD.

> **[T]ere are a few great examples of effective implementation which couldact as a model.**
>
> **-Dr Patricia Jackson**

FOREWORD - PROF RAJA MUKHERJEE MBE, MBBS, FRCPSYCH, PGDIP EPP, PHD

National FASD Experts Committee, Consultant Psychiatrist,
Clinical Lead Adult Neurodevelopment Disorder and FASD National Service

It was in 2019 that the journey to create NICE Quality Standard for FASD first began. Unfortunately, the pandemic paused the development and it was not until 2022 that they were eventually released. Two years later, it is interesting to think back and reflect on how much progress has been made.

Following the release of the Quality Standard, backed up by further work and expert consensus documents such as the *Time is Now* report, highlighting areas of good practise and how to implement the quality standards, unfortunately this current report reflects slow progress.

Too often it is a lack of understanding that inhibits pathway and service development. For example, a common statement made is that services are only commissioned for autism and ADHD. Yet, in many areas a priority group to access these pathways are those who have been in looked after children's services. These children, even if people do not realise it, are often individuals where prenatal alcohol is part of the history. This makes it highly likely that in a significant proportion of cases, alongside meeting diagnostic criteria for ASD or ADHD, would be FASD cases. This means that nearly every neurodevelopmental pathway in the country will be seeing cases of FASD, just not realising it. This fact alone should make clinicians and commissioners take note.

The NHS England FASD Health Needs Assessment highlighted various approaches to delivering services for FASD. The hub and spoke model of service delivery was one that was particularly emphasised because it offered local access to services, backed up and supported by expertise whilst confidence and services grow. Eventually it is hoped that national services would not be required. Instead, local individual clinicians would be backed up by regional hubs with multidisciplinary teams to see the more complex and unusual cases. This is a cost-effective way to deliver services with only minimal increases in current costs.

Some parts of the country have begun to develop this already. In my local area of Surrey in Kent this model exists. Wider relationships have also developed with Sheffield and Manchester. Simple more straightforward diagnostic cases are discussed in supervision with the central hub team. Where cases can be identified without the need for further referral they are clarified and signposted for management and support locally, with those more complex being signposted on to the specialist hub for a multidisciplinary team assessment. In Kent and Surrey this is already agreed as a process. In the other areas supervision only is available currently.

> **“[N]early every neurodevelopmental pathway … will be seeing cases of FASD, just not realising it. This should make clinicians and commissioners take note.”**
> **-Prof R Mukherjee**

Whilst a multidisciplinary assessment is always required, this can be through an individual collecting information locally in many cases. It does not have to be excessively expensive to deliver service, yet many areas have chosen to interpret guidance in a manner that precludes

service development rather than take a pragmatic approach to supporting individuals who are already being seen within their pre-existing service pathways.

Good practise documents are not being used in many areas to support development, meaning many individuals are still going either unrecognised or worse, excluded from service pathways by the false narrative that FASD is not commissioned rather than understanding that these are cases that are already being seen as they meet wider service specification requirements.

It appears there is still a long way to go but as a driver for change, Quality Standards should force individual practitioners to look at how they are delivering clinical services. Where there is a failure, it is inherent on the local commissioners and clinical experts to consider how this can be changed.

In a resource limited environment, it is possible to still deliver quality services, especially when many of these children are already sitting on referral waiting lists and are commonly seen, even if not thought about or recognised.

I hope that in the next two years improvements and changes will be seen.

(Note: Raja served as member of the NICE QS 204 committee but is writing this in his personal capacity.)

Table of Contents

ABOUT THIS PROJECT

The National Organisation for FASD sent Freedom of Information requests to all Integrated Care Boards in England and Health Boards in Wales to determine what action is being taken in response to NICE Quality Standard 204 on FASD[3] in the two years since it was issued on 16 March 2024. We also asked the Boards separately what services they have commissioned for diagnosis and management of people with FASD. In addition, we sent requests to NHS Trusts across England and Wales.[4] While we care deeply about what happens across the UK, NICE Quality Standard 204 applies to England and Wales, so this report focuses on those two nations. Scotland and Northern Ireland can use this to explore their own best practice.

This report is the first attempt at a comprehensive overview of action being taken based on NICE Quality Standard 204 to improve quality of care for some of society's most vulnerable and to see what we are doing to avert lifelong harm to developing brains of bodies caused by prenatal alcohol exposure since not only would improvements lead to personal gains for those with FASD and their families, but international research has shown the financial gains that come with prevention, early diagnosis and appropriate support. It follows National FASD's earlier report, "A Crisis of Commissioning"[5] (2017) that contributed to systemic change.

WHAT WE WERE LOOKING FOR AND LIMITATIONS OF THE APPROACH

At this point, we were simply trying to determine:

a) If the relevant bodies consider this NICE Quality Standard relevant;
b) Whether or not they have initiated action to track improvement in their quality of services;
c) If they have commissioned services for diagnosis and management for people of FASD across all ages.

We recognise the limitations of judging solely on the responses received as opposed to checking this against user experiences and other measures. But there has to be a starting point for getting a national picture. Imperfect as our questions and summaries may be, we present them in the hope that this report will help inspire policy makers in different localities to take a hard look at the responses and ask themselves if this is good enough. We hope NHS England might plan with us and fund a further joint audit as soon as is possible.

In this year's report we simply were primarily looking for some sign of action/ response to the NICE Quality Standard. We are well aware that just because an ICB or Trust says it's compliant with the QS does not mean that the improvements called for throughout the QS are cascading through the systems, nor that patient experience will reflect the best practice called for in the QS. We also appreciate that different Freedom of Information teams provide different levels of detail. We know that some of the responses received do not show the full picture in some areas. What responses do show is systemic confusion and a lack of coordination. For this report we had to go by the responses provided by the Freedom of Information teams. Finally, we are aware that some Trusts are highly specialised, but we still think they at least need training so they are ready should they have a role in care management of someone with FASD. We have provided case studies to show why this is true.

HOW WE EVALUATED RESPONSES RECEIVED

We decided it was best to provide readers with the responses received. We have included the

[3] Fetal Alcohol Spectrum Disorder, NICE Quality Standard 204 (2022). https://www.nice.org.uk/guidance/qs204

[4] Please note – we used the online "What Do They Know" portal and this allowed us to contact 212 of the 215 NHS Trusts. These included the 11 ambulance trusts but we have not included them in our figures.

[5] Crisis of Commissioning: CCGs are Failing Government Policy on FASD, National FASD (2017). https://nationalfasd.org.uk/documents/A%20Crisis%20of%20Commissioning%20report%20FINAL.pdf

questions asked and the responses in the Appendices in 3 sections:

- Integrated Care Board responses
- Welsh Health Board responses
- NHS Trust responses

Each entry has been screened to see what level of action we can determine from the response provided.

- **Taking action (green)** – These responses demonstrated that the ICB/ Health Board/ Trust appears to be taking some sort of systemic and ongoing action to improve and track improvements in quality of care across the 5 statements in NICE QS 204.
- **Taking partial action (amber)** – These responses indicated some action has been taken, but for example, they might not have considered all 5 statements of the NICE QS, they might not be tracking improvements in service, or there might have been some gap in the way they are demonstrating a response.
- **Not demonstrated it is taking action (red)** – These responses did not appear to indicate any further attempt to change/ improve their services following NICE QS 204. This could include some ICBs, Health Boards or Trusts who consider themselves 'compliant' but who are not implementing any changes nor seem to be using the indicators provided by NICE QS 204 to track improvements.
- **Did not reply by the statutory deadline (grey)** – This means the ICB/ Health Board/ Trust did not provide its response as required by law within 20 working days. Some responded to explain why. In order to allow us to go to press, we used this 20 days for the Trusts response as a cut-off. In a couple of instances we had delivery problems.

Please note, we have put a "response" hyperlink by every entry. Readers accessing the PDF version of this report on screen can use these links to see the actual correspondence and responses.

Even if the ICB, Health Board or Trust did not respond in time for this report preparation, do look, as their response might have come through and will be accessible via the link provided.

We have NOT at this time attempted to verify if the responses received match the real lived experiences of pregnant women and individuals with FASD and their families using the services. This is why we hope NHS England might partner with us on a future audit. We do note however that anecdotal feedback is that this still very much varies by postcode and within ICBs and Trusts. We regularly hear of pregnant women either not being asked or being given outdated and dangerous advice about alcohol in pregnancy.

Similarly, for FASD diagnosis and support it is rarely the case that it's a straightforward journey, despite the responses received and the great promise many felt at the time of the NICE Quality Standard publication. In future years' analysis we hope to dig a bit more into these aspects and may try to pursue progress made according to the measurable indicators that are included in NICE QS 204.

For this first report on the response to NICE QS 204, we are being generous. Any sign of action, task and finish groups, efforts to review policies, discussion of training, attempts to track indicators, etc all were accepted at face value and welcomed as at least initial steps toward improvement in quality of care.

We note that the NICE Quality Standard 204 is structured, as are all Quality Standards, to encourage demonstrable action to improve the quality of services outlined in the Quality Standard. This includes targeted suggestions for Commissioners, Trusts, and others (see box below). It also includes measurable indicators of progress.

The Quality Standard is not meant to be a tick box exercise. It's meant to be a guide to help local areas track improvement of care for a targeted population over time.

For those areas that consider themselves to be 'compliant' but who have not identified any changes in practice following NICE QS 204 and who are not using the indicators to track progress, this report provides an opportunity to see how others are responding. This is why we decided to include the replies. We want all policy makers to understand that the NICE Quality Standard 204 is deserving of attention and action, to connect with each other and to learn from best practice.

No ICB or Trust can claim to be fully compliant with the Quality Standard if they are not also tracking over time the provided demonstrable indicators to show they are improving their services to meet the need. Using a NICE Quality Standard is meant to be a dynamic exercise.

We recognise up front there are people of goodwill throughout the NHS who are trying their best to improve services in a difficult climate. Their efforts are deeply appreciated by people with FASD, their families and supporters. Our purpose is to draw more detailed attention to NICE QS 204, a key document from the National Institute for Health and Care Excellence, that can help them in their work to achieve better health for their areas and the nation.

WHY TRACKING IMPROVEMENTS CALLED FOR IN NICE QS 204 MATTERS

In 2020 OHID, then PHE, called reducing harms caused by alcohol in pregnancy a "public health priority…vital to ensuring that all children are given the possible start in life."[6]

Fetal Alcohol Spectrum Disorder can result from alcohol exposed pregnancies. A 2021 UK study showed it affects 2-4% of the population[7] – a rate higher than autism. According to SIGN 156, the diagnostic guideline in effect in Scotland, England and Wales, "Prenatal alcohol exposure should be *actively considered* [emphasis added] as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile." "A diagnosis of FASD is only made when there is evidence of pervasive brain dysfunction, which is defined by severe impairment [>2 standard deviations] in 3 or more … neurodevelopmental domains."[8]

DHSC says, "There is no 'mild FASD'. FASD is linked to a range of other conditions known as co-morbidities, which necessitate access to a multi-disciplinary team for long-term support."[9] DHSC says, "Receiving an early diagnosis can reduce the chances of adverse life outcomes."[10] Science and best practice on these issues have progressed since many practitioners had their training.

[6] Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy, Public Health England (2020). https://assets.publishing.service.gov.uk/media/5fd0b15ce90e0756207476c3/Maternity_high_impact_area_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf

[7] McCarthy et al (2021). https://onlinelibrary.wiley.com/doi/10.1111/acer.14705

[8] Children and young people exposed prenatally to alcohol, SIGN 156 (2019). https://www.sign.ac.uk/our-guidelines/children-and-young-people-exposed-prenatally-to-alcohol/

[9] Fetal alcohol spectrum disorder: health needs assessment, DHSC (2021). https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment

[10] DHSC (2021).

ABOUT NICE QUALITY STANDARD 204

Published in 2022, NICE Quality Standard 204 is a clarion call across England and Wales to ensure that we are improving quality of services for FASD prevention, diagnosis and support.

NICE Quality Standard 204 "covers assessing and diagnosing fetal alcohol spectrum disorder (FASD) in children and young people. It also covers support during pregnancy to prevent FASD. It describes high-quality care in priority areas for improvement."[11] It has five statements.

NICE QS 204 STATEMENTS

[11] NICE (2022).

Statements 1 and 2 are important since alcohol use in pregnancy is common. 77% UK women drink alcohol[12] and 45% of UK pregnancies are unplanned. [13] The UK has 4th highest rate globally – one study showed 41% drinking during pregnancy.[14] The top countries were Ireland (60.4%), Belarus (46.6%), Denmark (45.8%), UK (41.3%), Russia (36.5%). The UK rates are likely higher than 41%. As the DHSC Needs Assessment states, "The study does recognise significant limitations however, such as relying on people's memory to record alcohol use, and inconsistent data on drinking patterns." A UK cohort study[15] The proportion of women drinking during pregnancy (79%, 63% and 49% for trimesters 1, 2 and 3, respectively). The McQuire (2019)[16] study based on ALSPAC data also showed 79%. (This is compared to 11.5 % women smoke[17] in the UK and 8% smoke in pregnancy[18].)

Statements 3-5 are important because according to a gold-standard active case ascertainment study done by the University of Salford 2 - 4% have FASD.[19] This means more people have FASD than autism. (The WHO estimates 1% are autistic.)[20] The rates of FASD are higher for Children Looked After (27%)[21] and those who are adopted. One study showed a rate of prenatal alcohol exposure in 75% of adoption medicals[22]. Most people with FASD are undiagnosed. As the DHSC said, "The cognitive deficits, behavioural problems, psychopathology and other secondary disabilities associated with FASD affect an individual's ability to navigate their daily life and become independent adults."[23] These are the people in the systems for whom nothing seems to work - at great cost and frustration to the systems and with tragic implication for those individuals and their families and support systems. Statement 5 recognises that a management plan is needed "across a range of healthcare professionals, as well as education and social services[24]" in order to improve outcomes. This is an area where nearly all of the responses seem to fall short in recognising the role of the full range of services to accomplish this aim.

[12] NHS Digital, 2019. https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-alcohol/2019,
[13] PHE, 2018. https://www.gov.uk/government/publications/health-matters-reproductive-health-and-pregnancy-planning/health-matters-reproductive-health-and-pregnancy-planning
[14] Popova study (2017). https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30021-9/fulltext
[15] Nykjaer C, et al 2014 https://jech.bmj.com/content/68/6/542).
[16] https://www.sciencedirect.com/science/article/pii/S0091743518303323?via%3Dihub
[17] Office for National Statistic, 2022. https://backup.ons.gov.uk/wp-content/uploads/sites/3/2022/12/Adult-smoking-habits-in-the-UK-2021.pdf#-
[18] NHS Digital, 2023. https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-women-s-smoking-status-at-time-of-delivery-england/statistics-on-womens-smoking-status-at-time-of-delivery-england-quarter-1-2023-24
[19] McCarthy et al., 2021. https://pubmed.ncbi.nlm.nih.gov/34590329/
[20] WHO, 2023. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders
[21] Gregory et al. (2015). https://journals.sagepub.com/doi/abs/10.1177/0308575915594985?fbclid=IwAR3I8CvzzahXaKij84FXxG4GECUVwn2-thqILym0elNnwA2tROHOAWRnM4A
[22] Gregory (2015).
[23] DHSC, Fetal Alcohol Spectrum Disorder: Health Needs Assessment (2021). https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment
[24] Please note this report focuses on NHS response to NICE QS 204. There has as yet been no significant policy change/ update from education or social care services to ensure improvements in services relating to FASD prevention, diagnosis and support.

We present this report with positive intentions. We believe much more can be done and National FASD stands ready to work with ICBs, Health Boards and Trusts and in partnership with sister organisations in the FASD UK Alliance who are willing to work to ramp up services across the UK.

KEY FINDINGS

THE MAJORITY OF BOARDS AND TRUSTS ARE NOT TAKING ACTION ON NICE QS 204

Despite the great promise of NICE Quality Standard 204, two years after its publication nearly 53% of ICBs and 56% of NHS Trusts that replied to Freedom of Information requests are not taking action to meet the needs of this vulnerable population and to prevent alcohol-exposed pregnancies. In Wales all the health boards are taking at least partial action (but we note the lack of response from 2 of the 7 Boards might be skewing that perception of progress).

In addition, the vast majority of English Integrated Care Boards who replied by the deadline are not commissioning for diagnosis and management of care for children (70%), young people (73%), and adults (87%) and the majority of Welsh Health Boards have not commissioned services for diagnosis and management of people for children (67%), young people (67%) and adults (83%).

COMMISSIONING IS NOT HAPPENING – ESPECIALLY FOR ADULTS

Commissioning for FASD services is simply not happening in the vast majority of cases. ICBs should be given clear guidance by NHS England that they are expected to commission services to support FASD.

While beyond the remit of NICE Quality Standard 204, as FASD is a lifelong disability and remains largely undiagnosed[25] diagnostic pathways and services for people over 18 should also be implemented. That said, NICE QS 204 does state there is a need to carefully consider transitions. Since children become adults in the eyes of the healthcare system at the age of 16, too many with FASD or suspected FASD are in limbo during these key years if those practitioners working with them are not aware of the potential impact of FASD.

We note that only 5% of ICBs in England and 0% of Welsh Health Boards are providing commissioned services for adults with FASD.

[25] Schölin et al, "Fetal alcohol spectrum disorders: an overview of current evidence and activities in the UK," Archives of Disease in Childhood (2021), https://pubmed.ncbi.nlm.nih.gov/33441316/

Box: Summary of responses to National FASD's Freedom of Information requests about NICE QS 204*

RESPONSE TO NICE QUALITY STANDARD 204	Taking action (% of those who replied by statutory deadline)	Taking partial action (% of those who replied by statutory deadline)	Did not demonstrate taking action (% of those who replied by statutory deadline)	Did not reply by statutory deadline or had delivery problems
INTEGRATED CARE BOARDS - ENGLAND (36/42 RESPONDED BY THE STATUTORY DEADLINE)	11/36 (30.6%)	6/36 (16.7%)	19/36 (52.7%)	6/42 (14.2%)
HEALTH BOARDS -WALES (5/7 RESPONDED BY THE STATUTORY DEADLINE)	2/5 (40%)	3/5 (60%)	0/5 (0%)	2/7 (28.6%)
NHS TRUSTS ENGLAND/WALES (106 OF 211 RESPONDED, 11 AMBULANCE TRUSTS ARE EXCLUDED)[26]	16/95 (17%)	26/95 (27.3%)	53/95 (55.8%)	105/211 (49.8%)

*Questions posed are available in the appendices.

BOX: SUMMARY OF RESPONSES TO NATIONAL FASD'S FREEDOM OF INFORMATION REQUESTS REGARDING COMMISSIONING FOR DIAGNOSIS AND SUPPORT FOR FASD

"Has your ICB/ Health Board commissioned services for diagnosis and management of people with FASD?"	Commissioned (Green)	Partial (Amber)	No (Red)	Did not answer or reply by statutory deadline or had delivery problems
ICBs - England				
Children	2/40 (5%)	10/40 (25%)	28/40 (70%)	2/42 (5%)
Young people	2/40 (5%)	9/40 (22.5%)	29/40 (72.5%)	2/42 (5%)
Adults	2/37 (5.4%)	3/37 (8.1%)	32/37 (86.5%)	5/42 (12%)
Health Boards - Wales				
Children	0/6 (0%)	2/6 (33.3%)	4/6 (66.7%)	1/7 (14.3%)
Young people	0/6 (0%)	2/6 (33.3%)	4/6 (67.7%)	1/7 (14.3%)
Adults	0/6 (0%)	1/6 (16.7%)	5/6 (83.3%)	1/7 (14.3%)

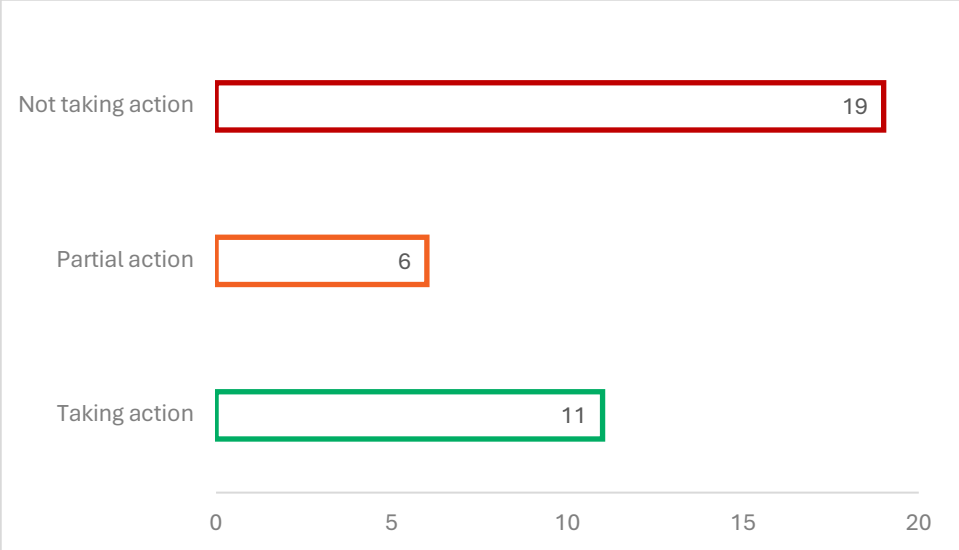
[26] Please note: We used the WhatDoTheyKnow portal for the requests and this allowed us to contact 211 of 215 NHS Trusts. We excluded the 11 ambulance trusts from our figures but have included other specialist trusts who may be called upon to contribute to management plans for people with FASD.

CHART: ICB RESPONSES – NICE QS 204 IMPROVEMENTS IN QUALITY OF CARE AND COMMISSIONING FOR DIAGNOSIS/SUPPORT

ICB Responses (36/42)

NICE QS 204 Improvements in Quality of Care

Not taking action – 53%
Partial action – 17%
Taking action – 30%



ICB Responses (40/42)

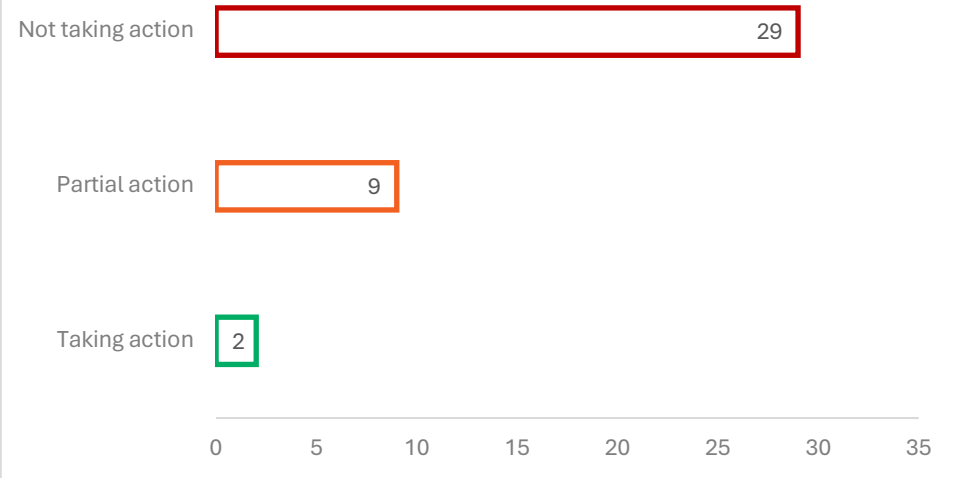
Commissioning for Child FASD Diagnosis/ Support

Not taking action – 70%
Partial action – 25%
Taking action – 5%

ICB Responses (40/42)

Commissioning for Young Person Diagnosis/ Support

Not taking action – 73%
Partial action – 22%
Taking action – 5%



ICB Responses (37/42)

Commissioning for Adult FASD DIagnosis/ Support

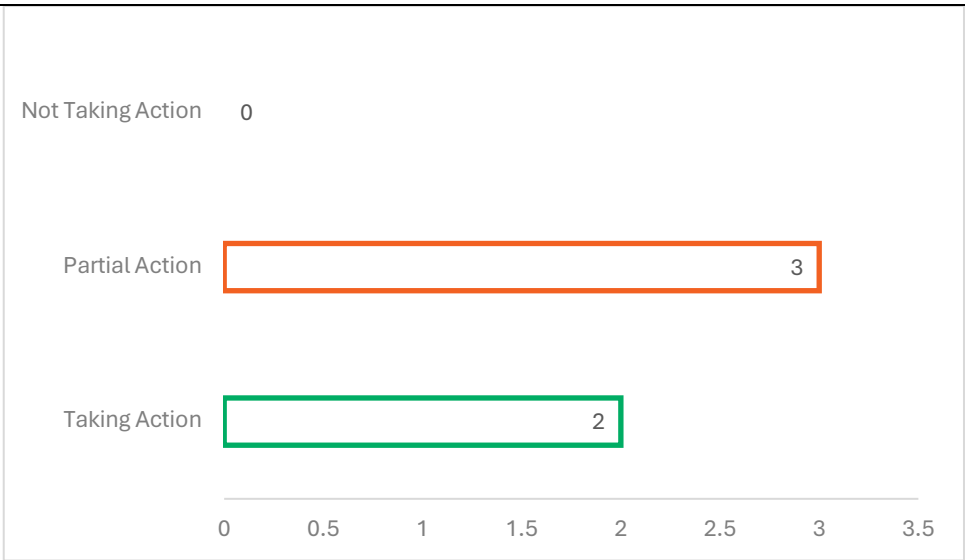
Not taking action – 87%
Partial action – 8%
Taking action – 5%

CHART: WELSH HEALTH BOARD RESPONSES NICE QS 204 IMPROVEMENTS IN QUALITY OF CARE AND COMMISSIONING FOR DIAGNOSIS/SUPPORT

WELSH Health Boards Responses (5/7)

NICE QS 204 Improvements in Quality of Care

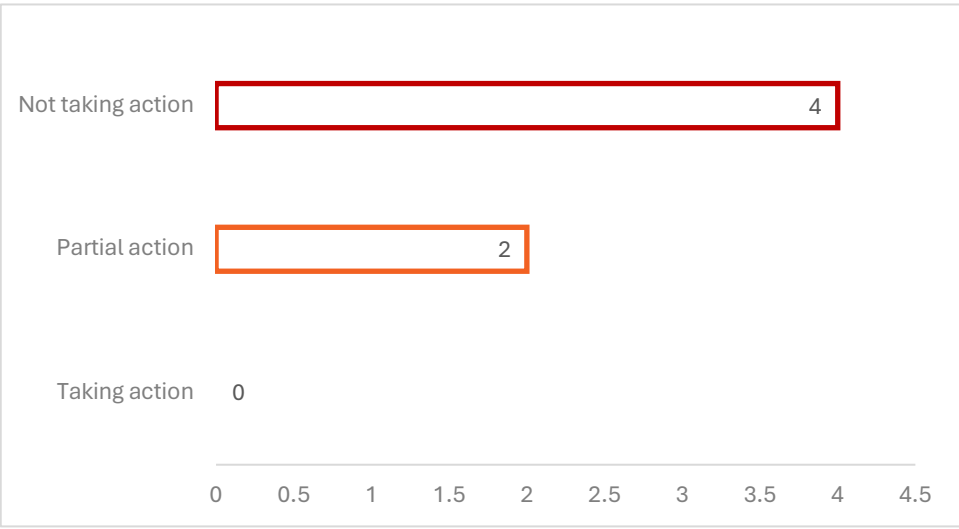
Not taking action – %
Partial action – %
Taking action – %



Welsh Health Boards Responses (6/7)

Commissioning for Child Diagnosis/ Support

Not taking action – 67%
Partial action – 33%
Taking action – 0%



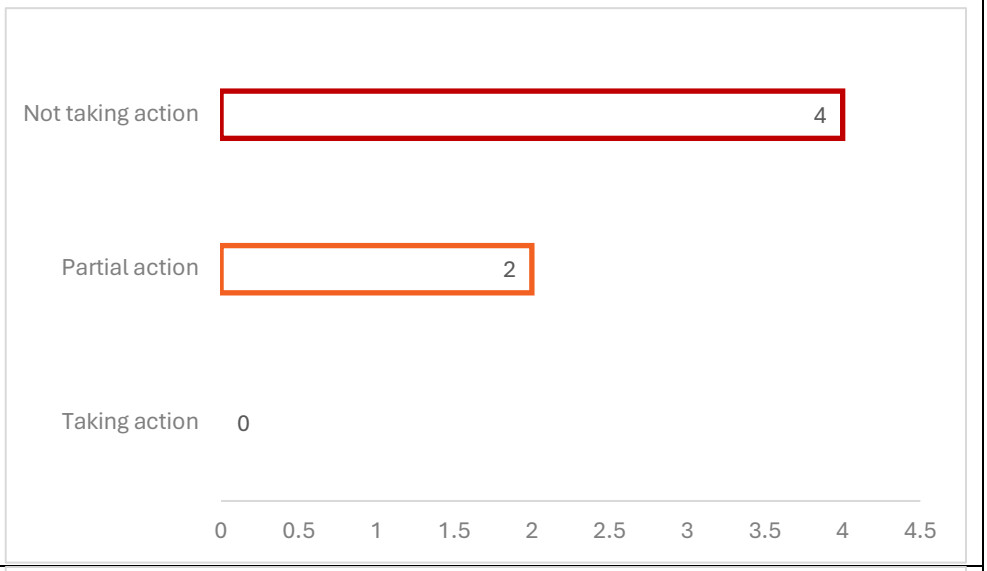
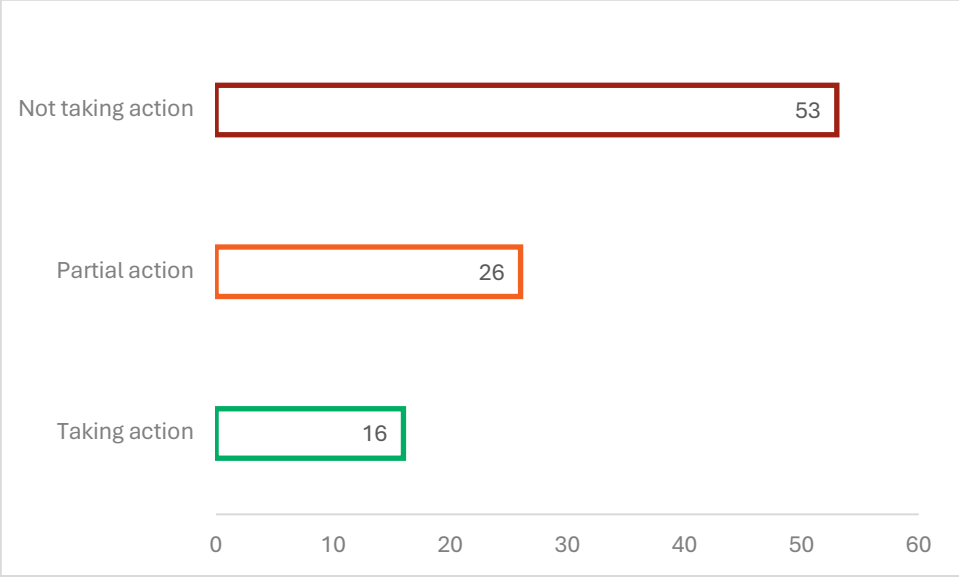
Welsh Health Boards Responses (6/7) **Commissioning for Young Person Diagnosis/ Support** Not taking action – 67% Partial action – 33% Taking action – 0%	
Welsh Health Boards Responses (6/7) **Commissioning for Adult Diagnosis/ Support** Not taking action – 83% Partial action – 17% Taking action – 0%	

CHART: NHS TRUST RESPONSES (ENGLAND AND WALES) NICE QS 204 IMPROVEMENTS IN QUALITY OF CARE

Trusts Responses (95/211)[27]

NICE QS 204 Improvements in Quality of Care

Not taking action – 56%
Partial action – 27%
Taking action – 17%



BOX: ICBS AND HEALTH BOARDS - SUMMARIES OF RESPONSES

Please see the appendix for full responses from ICBs, Health Boards and NHS Trusts.	**Progress on improvements called for in NICE QS 204**	**Has your ICB commissioned services for diagnosis and management of people with FASD (Fetal Alcohol Spectrum Disorder)**		
		children	young people	adults
NHS Bath and North East Somerset, Swindon and Wiltshire ICB				
NHS Bedfordshire, Luton and Milton Keynes ICB				
NHS Birmingham and Solihull ICB				
NHS Black Country ICB				
NHS Bristol, North Somerset and South Gloucestershire ICB				
NHS Buckinghamshire, Oxfordshire and Berkshire West ICB				
NHS Cambridgeshire & Peterborough ICB				
NHS Cheshire and Merseyside				
NHS Cornwall and Isles of Scilly ICB				
NHS Coventry and Warwickshire ICB				
NHS Derby and Derbyshire ICB				
NHS Devon ICB				
NHS Dorset ICB				
NHS Frimley ICB				
NHS Gloucestershire ICB				
NHS Greater Manchester ICB				

[27] Please note: We used the WhatDoTheyKnow portal for the requests and this allowed us to contact 211 of 215 NHS Trusts. We excluded the 11 ambulance trusts from our figures but have included other specialist trusts who may be called upon to contribute to management plans for people with FASD. Questions are provided in the appendices.

NHS Hampshire and Isle of Wight ICB				
NHS Herefordshire and Worcestershire ICB				
NHS Hertfordshire & West Essex ICB				
NHS Humber and North Yorkshire ICB				
NHS Kent and Medway ICB				
NHS Lancashire and South Cumbria ICB				
NHS Leicester, Leicestershire and Rutland ICB				
NHS Lincolnshire ICB				
NHS Mid and South Essex ICB				
NHS Norfolk and Waveny ICB				
NHS Northamptonshire ICB				
NHS North Central London ICB				
NHS North East and North Cumbria ICB				
NHS North East London (NEL) ICB				
NHS North West London ICB				
NHS Nottingham and Nottinghamshire ICB				
NHS Shropshire, Telford and Wrekin ICB				
NHS Somerset ICB				
NHS South East London ICB				
NHS South West London ICB				
NHS South Yorkshire ICB				
NHS Staffordshire and Stoke-on-Trent ICB				
Suffolk and North East Essex ICB				
NHS Surrey Heartlands ICB				
NHS Sussex ICB				
NHS West Yorkshire ICB				
Wales - Health Boards				
Aneurin Bevan University Health Board				
Betsi Cadwaladr University Health Board				
Cardiff and Vale University Health Board				
Cwm Taf Morgannwg University Health Board				
Hywel Dda University Health Board				
Powys Teaching Health Board				
Swansea Bay University Health Board				

TRUSTS - RESPONSE SORTED BY STATUS

Please note: We only included responses received by the statutory deadline. The links provided in the text will show any response received since the deadline, so please do check.

Taking action (green) – 16/95 replies that count toward figures = 16.8% (17%)

Taking partial action (orange) – 26/95 replies that count toward figures = 27.3% (27%)

Not demonstrated taking action (red) – 53/95 replies that count toward figures = 55.8% (56%)

Exempted (ambulance trusts) – 11/106 replies

Didn't reply 105/211 trusts in the What Do They Know system = 49.8% (50%)

Alder Hey Children's NHS Foundation Trust is taking action	
Central and North West London NHS Foundation Trust is taking action	
Cornwall Partnership NHS Foundation Trust is taking action	
Derbyshire Community Health Services NHS Foundation Trust is taking action	
Hampshire Hospitals NHS Foundation Trust is taking action	
Newcastle Upon Tyne Hospitals NHS Foundation Trust is taking action	
Northern Lincolnshire and Goole NHS Foundation Trust is taking action	
Oxleas NHS Foundation Trust is taking action	
Shropshire Community Health NHS Trust is taking action	
South Tees Hospitals NHS Foundation Trust is taking action	
South Tyneside and Sunderland NHS Foundation Trust is taking action	
Sussex Partnership NHS Foundation Trust is taking action	
Tees, Esk and Wear Valleys NHS Foundation Trust is taking action	
University Hospital Southampton NHS Foundation Trust is taking action	
University Hospitals Plymouth NHS Trust is taking action	
Walsall Healthcare NHS Trust is taking action	
Barnsley Hospital NHS Foundation Trust is taking partial action	
Birmingham Community Healthcare NHS Foundation Trust is taking partial action	
Blackpool Teaching Hospitals NHS Foundation Trust is taking partial action	
Cambridgeshire Community Services NHS Trust is taking partial action	
Central London Community Healthcare NHS Trust is taking partial action	
Chelsea and Westminster Hospital NHS Foundation Trust is taking partial action	
County Durham and Darlington NHS Foundation Trust is taking partial action	
Devon Partnership NHS Trust is taking partial action	
Great Western Hospitals NHS Foundation Trust is taking partial action	
Isle of Wight NHS Trust is taking partial action	

Kent Community Health NHS Foundation Trust is taking partial action
Leicestershire Partnership NHS Trust is taking partial action
Mid and South Essex NHS Foundation Trust is taking partial action
North West Anglia NHS Foundation Trust is taking partial action
Northamptonshire Healthcare NHS Foundation Trust is taking partial action
Northern Care Alliance NHS Foundation Trust is taking partial action
Oxford Health NHS Foundation Trust is taking partial action
Rotherham NHS Foundation Trust is taking partial action
Sheffield Children's NHS Foundation Trust is taking partial action
Sheffield Health and Social Care NHS Foundation Trust is taking partial action
South Warwickshire NHS Foundation Trust is taking partial action
St George's University Hospitals NHS Foundation Trust is taking partial action
University Hospitals of Derby and Burton NHS Foundation Trust is taking partial action
University Hospitals of Morecambe Bay NHS Foundation Trust is taking partial action
Worcestershire Acute Hospitals NHS Trust is taking partial action
Wye Valley NHS Trust is taking partial action
Airedale NHS Foundation Trust has not demonstrated it is taking action
Avon and Wiltshire Mental Health Partnership NHS Trust has not demonstrated it is taking action
Barnet, Enfield and Haringey Mental Health NHS Trust has not demonstrated it is taking action
Barts Health NHS Trust has not demonstrated it is taking action
Birmingham and Solihull Mental Health NHS Foundation Trust has not demonstrated it is taking action
Calderdale and Huddersfield NHS Foundation Trust has not demonstrated it is taking action
Cambridgeshire and Peterborough NHS Foundation Trust has not demonstrated it is taking action
Camden and Islington NHS Foundation Trust has not demonstrated it is taking action
Christie NHS Foundation Trust has not demonstrated it is taking action
Clatterbridge Cancer Centre NHS Foundation Trust has not demonstrated it is taking action
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust has not demonstrated it is taking action
Dartford and Gravesham NHS Trust has not demonstrated it is taking action
Derbyshire Healthcare NHS Foundation Trust has not demonstrated it is taking action
Dorset HealthCare University NHS Foundation Trust has not demonstrated it is taking action
Dudley Integrated Health and Care NHS Trust has not demonstrated it is taking action
George Eliot Hospital NHS Trust has not demonstrated it is taking action
Herefordshire and Worcestershire Health and Care NHS Trust has not demonstrated it is taking action
Hertfordshire Partnership University NHS Foundation Trust has not demonstrated it is taking action
Hounslow & Richmond Community Healthcare NHS Trust has not demonstrated it is taking action
Lancashire Teaching Hospitals NHS Foundation Trust has not demonstrated it is taking action
Leeds Teaching Hospitals NHS Trust has not demonstrated it is taking action
Lincolnshire Community Health Services NHS Trust has not demonstrated it is taking action

Lincolnshire Partnership NHS Foundation Trust has not demonstrated it is taking action	
Liverpool Heart and Chest Hospital NHS Foundation Trust has not demonstrated it is taking action	
Liverpool University Hospitals NHS Foundation Trust has not demonstrated it is taking action	
Mersey Care NHS Foundation Trust has not demonstrated it is taking action	
Milton Keynes University Hospital NHS Foundation Trust has not demonstrated it is taking action	
Norfolk and Suffolk NHS Foundation Trust has not demonstrated it is taking action	
Norfolk Community Health and Care Trust has not demonstrated it is taking action	
North Cumbria Integrated Care NHS Foundation Trust has not demonstrated it is taking action	
North Staffordshire Combined Healthcare NHS Trust has not demonstrated it is taking action	
Northumbria Healthcare NHS Foundation Trust has not demonstrated it is taking action	
Nottinghamshire Healthcare NHS Trust has not demonstrated it is taking action	
Queen Victoria NHS Foundation Trust has not demonstrated it is taking action	
Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust has not demonstrated it is taking action	
Rotherham Doncaster and South Humber NHS Foundation Trust has not demonstrated it is taking action	
Royal Marsden NHS Foundation Trust has not demonstrated it is taking action	
Royal National Orthopaedic Hospital NHS Trust has not demonstrated it is taking action	
Royal Orthopaedic Hospital NHS Foundation Trust has not demonstrated it is taking action	
Royal Papworth Hospital NHS Foundation Trust has not demonstrated it is taking action	
Royal Surrey NHS Foundation Trust has not demonstrated it is taking action	
Shrewsbury and Telford Hospital NHS Trust is not taking action	
Solent NHS Trust has not demonstrated it is taking action	
South West Yorkshire Partnership NHS Foundation Trust has not demonstrated it is taking action	
Tavistock and Portman NHS Foundation Trust has not demonstrated it is taking action	
Torbay and South Devon NHS Foundation Trust has not demonstrated it is taking action	
University Hospitals Bristol and Weston NHS Foundation Trust has not demonstrated it is taking action	
University Hospitals of Leicester NHS Trust has not demonstrated it is taking action	
Velindre NHS Trust has not demonstrated it is taking action	
Walton Centre NHS Foundation Trust has not demonstrated it is taking action	
Warrington and Halton Teaching Hospitals NHS Foundation Trust has not demonstrated it is taking action	
West Hertfordshire Teaching Hospitals NHS Trust has not demonstrated it is taking action	
Whittington Health NHS Trust has not demonstrated it is taking action	
East Midlands Ambulance Service NHS Trust exempted from results	
East of England Ambulance Service NHS Trust exempted from results	
London Ambulance Service NHS Trust is exempted from results	
North East Ambulance Service NHS Foundation Trust has been exempted from results	
North West Ambulance Service NHS Trust has been exempted from results	
South Central Ambulance Service NHS Foundation Trust has been exempted from results	
South East Coast Ambulance Service NHS Foundation Trust has been exempted from results	

South Western Ambulance Service NHS Foundation Trust has been exempted from results
Welsh Ambulance Services NHS Trust has been exempted from results
West Midlands Ambulance Service University NHS Foundation Trust has been exempted from results
Yorkshire Ambulance Service NHS Trust has been exempted from results
Ashford and St. Peter's Hospitals NHS Foundation Trust did not reply by the statutory deadline
Barking, Havering and Redbridge University Hospitals NHS Trust did not reply by the statutory deadline
Bedfordshire Hospitals NHS Foundation Trust did not reply by the statutory deadline
Birmingham Women's and Children's NHS Foundation Trust did not reply by the statutory deadline
Black Country Healthcare NHS Foundation Trust did not reply by the statutory deadline
Bolton NHS Foundation Trust did not reply by the statutory deadline
Bradford District Care NHS Foundation Trust did not reply by the statutory deadline
Bradford Teaching Hospitals NHS Trust did not reply by the statutory deadline
Bridgewater Community Healthcare NHS Foundation Trust did not reply by the statutory deadline
Buckinghamshire Healthcare NHS Trust did not reply by the statutory deadline
Cambridge University Hospitals NHS Foundation Trust did not reply by the statutory deadline
Cheshire and Wirral Partnership NHS Foundation Trust did not reply by the statutory deadline
Chesterfield Royal Hospital NHS Foundation Trust did not reply by the statutory deadline
Countess of Chester Hospital NHS Foundation Trust did not reply by the statutory deadline
Coventry and Warwickshire Partnership NHS Trust did not reply by the statutory deadline
Croydon Health Services NHS Trust did not reply by the statutory deadline
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust did not reply by the statutory deadline
Dorset County Hospital NHS Foundation Trust did not reply by the statutory deadline
Dudley Group NHS Foundation Trust did not reply by the statutory deadline
East and North Hertfordshire NHS Trust did not reply by the statutory deadline
East Cheshire NHS Trust did not reply by the statutory deadline
East Kent Hospitals University NHS Foundation Trust did not reply by the statutory deadline
East Lancashire Hospitals NHS Trust did not reply by the statutory deadline
East London NHS Foundation Trust did not reply by the statutory deadline
East Suffolk and North Essex NHS Foundation Trust did not reply by the statutory deadline
East Sussex Healthcare NHS Trust did not reply by the statutory deadline
Epsom and St Helier University Hospitals NHS Trust did not reply by the statutory deadline
Essex Partnership University NHS Foundation Trust did not reply by the statutory deadline
Frimley Health NHS Foundation Trust did not reply by the statutory deadline
Gateshead Health NHS Foundation Trust did not reply by the statutory deadline
Gloucestershire Health and Care NHS Foundation Trust did not reply by the statutory deadline
Gloucestershire Hospitals NHS Foundation Trust did not reply by the statutory deadline
Great Ormond Street Hospital for Children NHS Foundation Trust did not reply by the statutory deadline
Greater Manchester Mental Health NHS Foundation Trust did not reply by the statutory deadline

Guy's & St Thomas' NHS Foundation Trust did not reply by the statutory deadline	
Harrogate and District NHS Foundation Trust did not reply by the statutory deadline	
Hertfordshire Community NHS Trust did not reply by the statutory deadline	
Hillingdon Hospitals NHS Foundation Trust did not reply by the statutory deadline	
Homerton University Hospital NHS Foundation Trust did not reply by the statutory deadline	
Hull University Teaching Hospitals NHS Trust did not reply by the statutory deadline	
Humber Teaching NHS Foundation Trust did not reply by the statutory deadline	
Imperial College Healthcare NHS Trust did not reply by the statutory deadline	
James Paget University Hospitals NHS Foundation Trust did not reply by the statutory deadline	
Kent and Medway NHS and Social Care Partnership Trust did not reply by the statutory deadline	
Kettering General Hospital NHS Foundation Trust did not reply by the statutory deadline	
Kings College Hospital NHS Foundation Trust did not reply by the statutory deadline	
Kingston Hospital NHS Foundation Trust did not reply by the statutory deadline	
Lancashire & South Cumbria NHS Foundation Trust did not reply by the statutory deadline	
Leeds Community Healthcare NHS Trust did not reply by the statutory deadline	
Lewisham and Greenwich NHS Trust did not reply by the statutory deadline	
Liverpool Women's NHS Foundation Trust did not reply by the statutory deadline	
London North West University Healthcare NHS Trust did not reply by the statutory deadline	
Maidstone and Tunbridge Wells NHS Trust did not reply by the statutory deadline	
Manchester University NHS Foundation Trust did not reply by the statutory deadline	
Medway NHS Foundation Trust did not reply by the statutory deadline	
Mersey and West Lancashire Teaching Hospitals NHS Trust did not reply by the statutory deadline	
Mid Cheshire Hospitals NHS Foundation Trust did not reply by the statutory deadline	
Mid Yorkshire Hospitals NHS Trust did not reply by the statutory deadline	
Midlands Partnership NHS Foundation Trust delivery failure	
Moorfields Eye Hospital NHS Foundation Trust did not reply by the statutory deadline	
Norfolk and Norwich University Hospitals NHS Foundation Trust did not reply by the statutory deadline	
North Bristol NHS Trust did not reply by the statutory deadline	
North East London NHS Foundation Trust did not reply by the statutory deadline	
North Middlesex University Hospital NHS Trust did not reply by the statutory deadline	
North Tees and Hartlepool NHS Foundation Trust did not reply by the statutory deadline	
Northampton General Hospital NHS Trust did not reply by the statutory deadline	
Nottingham University Hospitals NHS Trust did not reply by the statutory deadline	
Oxford University Hospitals NHS Foundation Trust did not reply by the statutory deadline	
Pennine Care NHS Foundation Trust did not reply by the statutory deadline	
Portsmouth Hospitals University NHS Trust did not reply by the statutory deadline	
Princess Alexandra Hospital NHS Trust did not reply by the statutory deadline	
Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust did not reply by the statutory deadline	

Royal Berkshire NHS Foundation Trust did not reply by the statutory deadline	
Royal Cornwall Hospitals NHS Trust did not reply by the statutory deadline	
Royal Devon University Healthcare NHS Foundation Trust did not reply by the statutory deadline	
Royal Free London NHS Foundation Trust delivery error	
Royal United Hospitals Bath NHS Foundation Trust did not reply by the statutory deadline	
Royal Wolverhampton NHS Trust did not reply by the statutory deadline	
Salisbury NHS Foundation Trust did not reply by the statutory deadline	
Sandwell and West Birmingham Hospitals NHS Trust did not reply by the statutory deadline	
Sheffield Teaching Hospitals NHS Foundation Trust did not reply by the statutory deadline	
Sherwood Forest Hospitals NHS Foundation Trust did reply by the statutory deadline	
Somerset NHS Foundation Trust did not reply by the statutory deadline	
South London and Maudsley NHS Foundation Trust did not reply by the statutory deadline	
South West London and St George's Mental Health NHS Trust did not reply by the statutory deadline	
Southern Health NHS Foundation Trust did not reply by the statutory deadline	
Southport and Ormskirk Hospital NHS Trust did not reply by the statutory deadline	
Stockport NHS Foundation Trust did not reply by the statutory deadline	
Surrey and Borders Partnership NHS Foundation Trust did not reply by the statutory deadline	
Surrey and Sussex Healthcare NHS Trust did not reply by the statutory deadline	
Sussex Community NHS Foundation Trust did not reply by the statutory deadline	
Tameside and Glossop Integrated Care NHS Foundation Trust did not reply by the statutory deadline	
United Lincolnshire Hospitals NHS Trust did not reply by the statutory deadline	
University College London Hospitals NHS Foundation Trust did not reply by the statutory deadline	
University Hospitals Birmingham NHS Foundation Trust did not reply by the statutory deadline	
University Hospitals Coventry and Warwickshire NHS Trust did not reply by the statutory deadline	
University Hospitals Dorset NHS Foundation Trust did not reply by the statutory deadline	
University Hospitals of North Midlands NHS Trust did not reply by the statutory deadline	
University Hospitals Sussex NHS Foundation Trust did not reply by the statutory deadline	
West London NHS Trust did not reply by the statutory deadline	
West Suffolk NHS Foundation Trust did not reply by the statutory deadline	
Wirral Community Health & Care NHS Foundation Trust did not reply by the statutory deadline	
Wirral University Teaching Hospital NHS Foundation Trust did not reply by the statutory deadline	
Wrightington, Wigan and Leigh NHS Foundation Trust did not reply by the statutory deadline	
York and Scarborough Teaching Hospital NHS Foundation Trust did not reply by the statutory deadline	

Note: Ambulance Trust responses were not included in the tallies but we believe they should still have FASD training as many do for Autism and Learning Disabilities.

UNCLEAR LINES OF RESPONSIBILITY

It is unacceptable that so many of the nation's health care providers have a knee-jerk response still that this is not their responsibility. We are reminded of the game 'hot potato' where something is considered too hot to handle and is quickly passed to someone else. While FASD prevention, diagnosis and support has been determined by the country's leading public health bodies (DHSC, NICE, SIGN, PHE/OHID) to be a burning issue, in most cases the relevant parties are handing off responsibility to others while in the meantime people with FASD, their families, and pregnant women are being failed by a system meant to protect them.

The diffusion of responsibility is getting us nowhere. The ICBs say it is up to the Trusts to implement standards, but the Trusts say the services aren't commissioned.

Some community trusts say this is not their responsibility but the responsibility of acute trusts. This often shows a misunderstanding. We recognise there are variables at play, including where neurodevelopmental pathways, community paediatric services and CAMHS services are hosted. Some may be part of acute trusts others in different types of trusts. And yet, these types of blanket responses show the difficulties of not having central coordination or leadership on these issues. Too often this lack of coordination means NICE QS 204 is being ignored, resulting in the reality that the specified calls for improvements in quality of care do not get implemented.

We note that prenatal alcohol exposure can and does impact everything that is happening while the embryo/ fetus is developing in the womb. More than 428 conditions co-occur with FASD.[28] The DHSC says, "There is no 'mild FASD.'[29] Every medical professional regardless of specialism has a role to play in treating and supporting individuals who have or may have FASD. Every part of the medical profession should consider that at least a part of NICE QS 204 applies to them in their roles. People with FASD and their families all have stories of the distress and set back in care it can cause when specialist services do not understand FASD.

In addition, women use services across the NHS. They might be pregnant or could become pregnant or they could have FASD themselves. This is why it's important that cross sector training is done as called for in NICE QS 204.

This matters because key segments of the population still don't understand the advice. A February 2024 nationally representative poll of adults conducted by OnePoll for National FASD showed that 20% of adults still do not recognise the CMOs guidance nearly 8 years after the guidance changed. Nor did, alarmingly, 34% of adults aged 25-34 (key childbearing years). In London, 33% of adults did not recognise the guideline.

Many Trusts still view FASD as the responsibility of maternity and neonatal teams, thereby missing the point of the Statements 3-5 in NICE Quality Standard 204. (They also may well be missing the opportunity for proactive FASD prevention as this is not covered in the NICE Quality Standard.)

[28] Popova et al., 2016. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01345-8/fulltext,

[29] DHSC (2021).

FAILURE TO USE NICE INDICATORS FOR TRACKING IMPROVEMENTS IN SERVICES OVER TIME

In only very rare instances did any ICB or Trust report that it is using the indicators provided by NICE to track improvements in services over time, which is the main point of a Quality Standard.

TRAINING REVIEWS ARE NEEDED BEFORE CLAIMING COMPLIANCE WITH NICE QS 204

ICBs and Trusts cannot rely on being compliant with NICE QS 204 without additional training in FASD. Those who have said they are 'compliant' should review what training their staff has had and begin tracking their progress via the indicators suggested in NICE QS 204.

We also note that many replies rely on GPs being trained in recognition and understanding the local FASD pathway, but such training was rarely demonstrated in the responses.

While we recognise some Trusts are specialised, they still must recognise their teams will need FASD training as they will be part of care management for people with FASD throughout their lifespan. They will encounter people with FASD during some of their most difficult hours and their training as called for in NICE QS 204 (and the DHSC FASD Health Needs Assessment) is critical. For example, mental health trusts generally don't recognise their role in care management of those with FASD as outlined in Statement 5 despite the fact that some 90% of people with FASD have mental health challenges[30]. Early identification and supports may decrease the numbers with what are often secondary mental health problems.

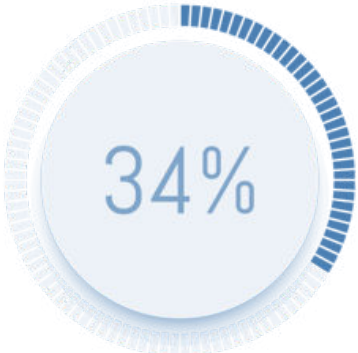
Several responses spoke about FAS (Fetal Alcohol Syndrome). Use of this phrase is an automatic indicator that the training is not current and there is a need for a local audit of information to ensure compliance with SIGN 156 and a hard look at any sense of complacency that the area is complying with NICE QS 204.

LOCAL PATHWAYS ARE UNCLEAR AND UNDER RESOURCED

It is interesting that many ICBs have talked about including FASD as a possible diagnosis in their neurodevelopmental pathways, but few have recognised the need to increase commissioned resources to allow for the extensive ND assessments needed to complete the FASD diagnostic assessment. Nor have they looked at proactively commissioning FASD support resources for when these children and young people are diagnosed.

For those areas that rely solely on sending cases to the national clinic, because of the prevalence they should really have local provision for diagnosis with recourse to a national resource if they are unsure of the diagnosis – the Hub and Spoke model. NHS England should provide seed funding for this. Most local areas have local facility for diagnosis of autism therefore with FASD training as called for in NICE QS 204 and revisiting the pathways they should be able to set up diagnosis locally.

While outside the scope of this study, we note that with Right to Choose, many are accessing with public funding private routes to diagnosis that may/not be FASD trained/informed and compliant with NICE QS 204. We also are aware in some areas social services are commissioning diagnosis out of area, but that is outside the scope of this report.



34% of 25-34 year-olds nationally did not recognise the CMOs guidance on alcohol & pregnancy

[30] Streissguth et al., 2004. https://pubmed.ncbi.nlm.nih.gov/15308923/.

GOVERNMENT GREEN PAPERS IN ENGLAND AND WALES AND AN FASD PREVENTION AND RESPONSE FUND AND ACT ARE NEEDED

Given this lack of commissioning and patchy response to NICE QS 204 across England, National FASD once again calls for a Government Green Paper on FASD Prevention and Response - looking into the response to NICE Quality Standard 204 as well as the DHSC FASD Health Needs Assessment. This should lead to an FASD Prevention and Response Act, that should include an FASD Prevent and Response Fund equivalent to 0.1 or 0.2% of the alcohol duty. Similarly we call for a Welsh Government Green paper on FASD Prevention and Response, focusing on NICE QS 204 and implementation of SIGN 156.

THIS REPORT IS JUST THE START, FUNDING IS NEEDED FOR MORE IN-DEPTH TRACKING OF THE RESPONSES TO NICE QS 204

There is need for continued tracking of the progress on improvements of services as called for in NICE QS 204. We call for NHS England to work with us and fund a further joint audit as soon as is possible.

BOX: ACCORDING TO GOVERNMENT ICBS HAVE A DUTY TO CONSIDER FASD AND IMPLEMENTATION OF NICE QS 204

We quote at length here the Government's response to Steve Barclay, then Health Secretary about the intention of what ICBs should be doing regarding NICE Quality Standard 204.

"[U]nder the Health and Care Act 2022, integrated care boards (ICBs) must set out in their plans the steps they will take to address the particular needs of children and young people under the age of 25 in their local area. … [S]tatutory guidance on executive lead roles within ICBs was published on 9 May, which designates the need to identify lead members of the board with explicit responsibility for the following population groups:

- children and young people (aged 0 to 25);
- children and young people with special educational needs and disability;
- safeguarding (all-ages); and
- learning disability and autism (all-ages).

This guidance can be accessed at www.england.nhs.uk/publication/executive-lead-roles-within-integrated-care-boards.

These lead board members within local ICBs are expected to make decisions around service provision relating to these population groups based on assessment of need in the area. This should include consideration of FASD and implementation of the NICE FASD Quality Standard." *[Emphasis added] (Neil O'Brien MP Parliamentary Under Secretary of State for Primary Care and Public Health to Steve Barclay MP, 15 June 2023)*

The ICBs that replied by the statutory deadline offered very varied answers as to who was leading on NICE QS 204. Over a third said no they didn't have a lead or that they had no data. Others said that it was up to the trusts or individual providers. Several only suggested leads in maternity or neonatal services, which does not take account of diagnosis which for the majority will take place over the age of six. Some areas had recognised that there needs to be leads within different specialisms, one area listed: Maternity, midwifery, Health visitors, primary care, paediatrics, neurodevelopmental clinical assessment. Beyond the scope of the Quality Standard, but still essential, none of the ICBs that replied had anyone specifically leading on adults, SIGN 156 (2019) says that diagnostic criteria in adults is the same as for younger individuals.

It appears from responses that there is confusion among ICBs that their leads as identified above in the quote from the minister are taking NICE QS 204 into account in their duties to improve quality of care.

WHAT IS A NICE QUALITY STANDARD - AS DEFINED BY NICE?

There is confusion out there about what NICE Quality Standards are. We quote at length here from NICE to explain what they are. They are different from NICE guidelines.[31]

According to NICE[32], "NICE quality standards focus on a few key priorities within a defined area of care that are most likely to need improvement, along with providing information about how to measure progress." "[Q]uality standards set out priority areas for quality improvement in health, public health and social care."[33]

"Our quality standards play a key role in helping commissioners and providers. They can:

- support in identifying changes that need to be made in order to develop services
- empower providers to ask for the specific support they need to improve service performance and quality
- provide commissioners with key quality markers that they can include in service specifications."[34]

"Quality standards are helpful for:

- setting the baseline that providers are expected to meet
- underpinning policies and procedures."[35]

"Quality standards can be used for:

Quality improvement

- identifying areas for quality improvement
- designing and conducting audits
- writing improvement and action plans
- demonstrating the level at which services should be provided/setting goals
- training and education.

Quality assurance and monitoring

- developing frameworks for quality assurance
- identifying gaps in services, benchmarking and monitoring/tracking changes

[31] Please note: National FASD's chief executive Sandra Butcher served as a lay member of the NICE QS 204 committee, along with Trustee Roisin Reynolds and two members of National FASD's Experts Committee – Prof Raja Mukherjee, Dr Inyang Takon.

[32] https://www.nice.org.uk/about/what-we-do/into-practice/resources-help-put-guidance-into-practice/how-guidance-standards-help-yous.

[33] https://www.nice.org.uk/standards-and-indicators/how-to-use-quality-standards

[34] https://www.nice.org.uk/standards-and-indicators/how-to-use-quality-standards

[35] https://www.nice.org.uk/standards-and-indicators/how-to-use-quality-standards

- setting key performance indicators (KPIs) and monitoring performance
- evidence of service quality for regulators.

Influencing commissioning
- identifying support or changes needed to improve services
- supporting business cases along with requests for funding and resources.

Are they mandatory?
- Our quality standards are not mandatory. But they do support the government's vision for a health and care system focused on delivering the best possible health outcomes." [36]

"Quality standards prepared by NICE are provided for by the Health and Social Care Act 2012. The Secretary of State and NHS England (The National Health Service Commissioning Board) must have regard to quality standards prepared by NICE in discharging their respective duties as to improvement in the quality of services provided in the health service."[37]

"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."[38] [*Emphasis added*]

"It is important to recognise that the development of good guidelines does not automatically ensure their use in practice. …. it is recommended that in order to maximise the likelihood of guidelines being used **there is a need for coherent dissemination and implementation strategies that deal with any obstacles to implementation that have already been identified**" [*Emphasis added*]. [39]

[36] https://www.nice.org.uk/standards-and-indicators/quality-standards#are-they-mandatory

[37] https://qualitystandards.trixonline.co.uk/chapter/about-the-quality-standards

[38] https://www.nice.org.uk/guidance/qs204/chapter/About-this-quality-standard

[39] "Principles underlying the development of clinical guidelines, clinical effectiveness and quality standards, and their application in health and social care," UK Faculty of Public Health. https://www.healthknowledge.org.uk/content/principles-underlying-development-clinical-guidelines-clinical-effectiveness-and-quality

HOW CAN YOU USE THIS REPORT?

SERVICE USERS - IF ARE PREGNANT, OR HAVE FASD OR ARE A PARENT/ CARER/ GUARDIAN –

- Look to see what your ICB/Health Board and local NHS Trust are saying about NICE QS 204.
- Share your experiences accessing services in your area in the last year with National FASD.
- Share your experiences about local services via your Trust's patient feedback systems. Most of the Trusts will have a section on their website for this. Has the service given the latest guidance? Have the professionals you encountered been informed of the risks of alcohol in pregnancy or did they understand FASD?
- Write to your commissioners and give them your reaction to what was provided here.
- Write to your MP.
- Find your local FASD UK Alliance support group (https://fasd-uk.net) and see what you might collectively do in your area to push for change or to join in efforts already underway.
- Use social media to call attention to this issue.

PRACTITIONERS

- If you are trying to help your area gear up, use these responses (and compare them to others) to demonstrate what more could be done to improve services.
- Ask for more training and access to the training that currently exists to improve professional practice – including RCPCH, FAAST University of Edinburgh courses, training from National FASD and other FASD UK Alliance groups .
- Start a local group of like-minded practitioners.
- Check out *The Time is Now: The National Perspective on Ramping Up FASD Prevention, Diagnosis and Support Services* for ideas on how to move forward, based on best practices across the country based on a series of 9 roundtables with more than 60 commissioners, practitioners, researchers, people with lived experience. https://nationalfasd.org.uk/learn-more/policy/innovation-best-practice/

SERVICE PROVIDERS

- Use the report and the below chart to think about other steps that can be taken to ensure you are working to improve quality of care for your service users.
- Meet with local support groups and stakeholders to begin or further discussions. You can find independent local groups via the FASD UK Alliance - https://fasd-uk.net
- Contact National FASD if you would like a discussion about best practice or to join a roundtable on ways to improve quality of care for this population.
- Look closely at your neurodevelopmental, autism and learning disability pathways and provisions to ensure adequate training, diagnosis and support.
- Provide funding for alcohol and pregnancy awareness campaigns.
- Follow the additional steps outlined in the box below summarising suggestions from NICE included in NICE QS 204.

COMMISSIONERS

- Ensure your relevant lead board members (as outlined by Government's response to Steve Barclay shown in preceding box), have had training and are overseeing improvement in quality of care for this population;
- Ensure your commissioning is providing training for maternity teams that is current with the latest guidance and

NICE QS 204 and that you are providing for awareness raising among the population about the CMOs guidelines;

- Ensure you are commissioning for a diagnostic pathway that is in line with SIGN 156 (the diagnostic guideline in effect across England, Wales and Scotland) and NICE QS 204.
- Follow the additional steps outlined in the box below summarising suggestions from NICE included in NICE QS 204.
- Work with The National Organisation for FASD or other members of the FASD UK Alliance to explore ways forward for your area, with input from those with lived experience.

BOX - WHAT NICE QUALITY STANDARD 204 ON FASD MEANS FOR ICBS AND TRUSTS

The following excerpts from NICE QS 204 show that commissioners and services provides should be taking action

Statement	Commissioners	Service providers
Statement 1 - Pregnant women are given advice throughout pregnancy not to drink alcohol.	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.	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.
Statement 2 - Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.	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.	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.
Statement 3 - Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.	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.	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.
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.	Commissioners (such as clinical commissioning groups or integrated care systems) commission services for neurodevelopmental assessments that consider FASD as a diagnosis.	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.

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

ADDITIONAL SUGGESTIONS FROM NICE AS TO WHAT CAN BE DONE LOCALLY:

- "Connect, gather and share information with other interested people. Start your own local Meetup group to find interested people. Or get the conversation started using Whatsapp or other social media.

- Run a webinar or online meeting to find out how services currently work.

- Audit your service against NICE guidance or standards at the same time as running a national audit to save time.

- Record the results in a spreadsheet you can share easily so everyone can see the current picture."[40]

- "Take the information you gathered in the last step and map the results against our guidance or quality standards. Note what you are doing already, what might need to change and what is missing or might need to be stopped. Now you need to decide what actions could be done to meet the guidance. This is a great opportunity to work with a range of people who work in the service or who are using the service. Together you can co-produce an improved service, or even a new service, building on everyone's different perspectives and knowledge. Sometimes small changes can make a difference quickly. But perhaps bigger changes are needed and a long-term plan that can be broken down into a series of steps and delivered over a longer period is best. Coordinate actions across services or communities to reduce duplication and improve how services link together. You need to work with your business planning team to estimate the resource impact of each action. You may be able to show how it will save money or resources. Remember to set out timelines and milestones and consider staffing and training. Your action plan should also include information on how you will measure the effect of the changes. Think about where you can get the data you need and how it will be collected."[41]

[40] https://intopractice.nice.org.uk/practical-steps-improving-quality-of-care-services-using-nice-guidance/index.html

[41] https://intopractice.nice.org.uk/practical-steps-improving-quality-of-care-services-using-nice-guidance/index.html

BOX – ECONOMIC IMPACTS OF INACTION

This excerpt is from the *DHSC FASD Health Needs Assessment for England* (2021)[42]

"FASD incurs personal costs to the individuals and families affected, but the burden of need it creates on society carries a significant financial cost also. The cognitive and behavioural difficulties mean that these costs go beyond health and care, extending to the education and justice systems also. Coupled to this, when people living with FASD cannot obtain the support they need, there is a substantial loss in productivity.

"Data on the economic costs of FASD in the UK are limited, and economic analyses from other countries are reliant on assumptions that may not be applicable in other settings. Nevertheless, there are some global studies that offer insight in to the potential impacts FASD could be having on the UK economy and give a sense of the potential scale of the costs involved. Using older data from the US, **the BMA cite an estimated annual cost of FASD to the United Kingdom of £2 billion.**[footnote 13] One of the most significant elements of these costs relates to lost productivity. One Canadian study assessed productivity losses, calculated with consideration of the variable severity of mental impairment caused by FASD.[footnote 79] They found that 0.03% of the Canadian workforce experiences a loss of productivity because of impairments caused by FASD. This translated in an aggregated loss to the economy of between CND $418 million (£258 million) to $1.08 billion (£0.67 billion).

"These numbers are substantial but should also be considered from the individual perspective. The study estimated that a worker with FASD could be expected to earn 7.8% to 16.2% less than if they did not have FASD.

"A recent systematic review covering 4 other countries (US, Canada, Sweden and New Zealand) estimated the annual costs of care for children with FASD to be $22,810 (£18,008) and for adults $24,308 (£19,192). Residential costs for children with FASDwere 4-fold greater than for adults with FASD. The costs of lost productivity for adults were 6.3-fold greater than for children.[footnote 80]

"Canadian research also offers cost estimates for the full evaluation required to diagnose FASD,[footnote 81] with the most conservative estimate of 32 to 47 hours required for an individual to be screened, referred, admitted and diagnosed. The total cost ranged from CND $3,110 to $4,570 per person. In Canada, this equates to a national cost from CND $3.6 million to $7.3 million, although differences in population and extent of service provision make the latter figures difficult to translate to the UK context. A systematic review from 2017[footnote 82] did not identify any studies exploring the cost-effectiveness of diagnosing FASD, and it identified only a single study to explore the question of cost-effectiveness of the treatment of FASD in individuals of any age.[footnote 83]

"This cost-benefit analysis found that a service network aiming to reduce the occurrence of secondary disabilities from FASD in Alberta, Canada, would 'break-even' if the service was 28% effective. That is to say, **if the service was able to prevent 28% of disabilities that would otherwise occur, it would be cost neutral; any more effective than this and there would be an overall cost saving."** *[Emphasis added]*

[42] FASD Health Needs Assessment for England, DHSC (2021). Please see original for the linked footnotes. https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment

CASE STUDIES - STAKEHOLDERS ON THE IMPORTANCE OF ALL SERVICES ADDRESSING NICE QS 204

While it is beyond the scope of this report to supplement the claims made by ICBs, Health Boards and Trusts with the lived experience of stakeholders in each of the areas, we offer some case studies to shed more light on why even highly specialised Trusts should be taking action on NICE QS 204 and why the training called for in NICE QS 204 is urgently needed. These 14 case studies are the tip of the iceberg. Every person with FASD and every family will have similar examples of the lack of training, pathways and informed support.

BIRTH MUM SEEKING DIAGNOSIS FOR CHILD AND PROBLEMS FOR CHILD ACCESSING SERVICES AS AN A&E, OPHTHALMOLOGY AND CAMHS PATIENT

My son D, who is now 16 years old, was diagnosed with FASD at the age of 9 years old. I didn't tell him straight away as I felt I needed time to come to terms with the news and to adjust. D was also in a new school and facing challenges of his own. Maturity wise he was still quite young and I didn't feel I could explain it to him in a way he would understand or accept at the time.

The diagnosis itself was not a speedy process. It started as a referral to one paediatrician who knew absolutely nothing about FASD and simply accused me of having a guilt complex. She was about to discharge D but I asked her to refer D to another paediatrician, who was knowledgeable about FASD. Thankfully she referred us and a few months later we had another appointment with the new paediatrician. The stages from there were multiple assessments with an Occupational Therapist, CAMHS, school-based observations etc. After two years he received his diagnosis of (at the time) partial – FAS (FASD without sentinel facial features). This was incredibly difficult to hear, being D's birth mother, however I was pleased D could start getting help. We finally had an answer and foundation from where to begin.

I wanted to explain the initial stages so that you can understand that FASD isn't simply something that is plucked out of a hat. It's not a label we simply gave to D, without endless, exhaustive assessments. It's a difficult process as D was, at times, not very cooperative with the professionals. It wasn't his fault. They were long and sometimes boring, confusing at times and sometimes intrusive.

I eventually told D when he was 10 years old. He knew he was different than other kids and was struggling with his mental health and self-esteem. I knew it was time for him to know the reason why he struggled with behaviours, social and emotional mental health, sensory issues and speech. D took the news really well and was thankful to have a name to put to his problems. It was a huge relief. From there I educated him on FASD. Taught him that there is absolutely nothing bad or wrong about him, he just has a brain which works differently to others, because of my actions when I was pregnant with him. He accepted himself and started to improve.

Then the first challenge came our way, in the form of an emergency hospital visit. D contracted Invasive Strep A when he was 10 years old, his last year of primary school. A secondary condition developed called Peri-Orbital Cellulitis, causing an abscess to form behind his right eyeball. Not only had D been rushed into hospital, put in isolation, had multiple bloods drawn and IV's inserted, he was now facing emergency surgery to save his eyesight.

Being in hospital, D coped really well the first week or so as he was so poorly. He was quite sedate the first week and allowed the doctors to do the regular IV changes and tests. However as the antibiotics began to work D started to become more agitated and uncooperative with the doctors. I had explained to them about his FASD and how that impacted on his sensory needs, anxiety and understanding. D became fearful of the IV changes and started to refuse to allow them. I tried asking the doctors for mild sedation when it came to these procedures but

they refused. They stated that they needed a psychiatric assessment to confirm that D needed the mild sedation. D had by now had the operation on his eye and was recovering well, but he still needed the antibiotics intravenously to prevent the abscess from growing back and to completely strip the Strep A from his blood. It got to the point where D became so terrified he ran and hid in the play room to try and escape the nurse performing the IV change. He picked up a child's chair and any time she came near him, he raised it to keep her back. She then threatened him with security for being aggressive and violent! There was no attempt at de-escalation. No acceptance that D's anxiety was now controlling his ability to allow the nurses to help him medically. He was seen purely as a naughty child.

With regards, to D's eye, he had had the surgery and a tube was placed in by his eye to drain the fluid. They gave him sedation in his room, a few days later, to remove the tube easily. However, when he had another MRI, the abscess was still present and he'd need further surgery. This time though, D knew what this meant. We couldn't trick him down to the operating theatre as he was aware now of what that meant. Going to sleep and waking up in pain. I asked them to sedate him on the ward so that we could get him down to the operating theatre, but they refused. He wouldn't accept the sedation once down there and became extremely distressed, to the point where the doctors said that he was in too much of a heightened state and the anaesthetic would most likely be ineffective. They gave up. They said they would just have to hope that the antibiotics he was taking would be enough to destroy the abscess.
When I had spoken to the nurses and doctors in the children's ward about FASD, none of them had a clue what I was talking about. They said they had never encountered it before. I took in leaflets and print outs of information. Guides for professionals, techniques on how to help D around his anxiety and "defiance". To this day I don't believe any of them read the information. Eventually, they discharged D with an old IV still in his arm. We had to go back to hospital every day for treatment and soon enough, the old IV failed. D was not able to allow them to fit a new one as it was so painful. So they gave him adult doses of a strong antibiotic. This turned his teeth brown so they looked like wood. This made D incredibly self conscious. It took years for that colour to fade away.
If the dosage of antibiotics wasn't enough, there was a high chance the abscess would re-manifest and he was at risk of losing his sight. Thankfully, his last MRI was clear and the nightmare was over.

The events that took place at the hospital have traumatised D terribly. He will not go back to the same hospital it all happened in. He has incredible anxiety at the thought of needing a hospital visit, if he's sick or has an accident. It wasn't just the illness that has left a scar on him, it's the mental torture he went through there. The lack of compassion and understanding was astounding. The threats of security and shouting. The lack of interest in learning about D's FASD diagnosis and therefore being able to help him. The exasperation thrown in my direction, for not being able to "control" D and make him compliant.

The second time we encountered FASD being cast aside was at D's 6 monthly CAMHS meeting. He had yet another psychiatrist who, in his own words, "does not agree with FASD as a diagnosis". He was more proficient with Attachment Disorder and after one 45-minute meeting with D, decided that D didn't have FASD, he had Reactive Attachment Disorder. This was apparently caused by me "not parenting him properly because of his father's domestic violence" towards me. Not only did he tell me this away from D, where I asked him to please let me digest this and then talk to D about it myself, but as soon as D came back into the meeting, he openly told D that this was what was wrong with him. He told D that I had clearly struggled as a parent and this had caused his problems, not FASD. D became quite upset and angry. He was confused but also very protective of me. He felt that this man had said something bad about me and he didn't like it. This made D withdraw from him. Each meeting from then on was extremely difficult as everything I said was ignored or twisted by the psychiatrist. I had by now researched RAD and did not agree that this was the cause of D's problems. The diagnosis of FASD took two years of assessments and tests to confirm. How could he make an informed diagnosis in only one 45-minute session? I made a complaint to the manager at CAMHS. Not only did this person say

things to D that I felt was inappropriate in timing and with lack of compassion, he also took D's FASD diagnosis off his records!

Eventually this doctor left. The next one D saw was knowledgeable about FASD and reinstated that diagnosis and took off the RAD diagnosis. D has been with him ever since. The way we were spoken to by the previous doctor and the lack of acknowledgement of his existing conditions caused D to form a huge mistrust in the service. He didn't like me being spoken down to like that. He didn't know what to believe about his difference diagnosis. He didn't want to see a new doctor, or any doctor come to that, but he had to because of his medications. His anxiety was extremely high at every meeting from then on, as he was on constant edge. He simply didn't have faith in these professionals any more.

D's experiences over his journey with FASD have been a mixture of positive and negative. The positive experiences have always related to professionals who know about FASD and accept him for who he is. Who understand his needs and meet them. His negative experiences, many many negative experiences, have always been with professionals who don't know about FASD and who refuse to read up or educate themselves about it. They tell him he MUST be able to control himself, complete assessments and attend school. His anxiety reached heights where he couldn't even get out of bed or leave his bedroom for days.

For me personally, these experiences have been incredibly frustrating and belittling. To be told it's my parenting, my "lack of boundaries", my inability to control D. My apparent failure as a Mother. I myself ended up being treated for anxiety and depression. Social Services were involved and even they had no idea what FASD was. Cases were closed, no support given.

Hopefully we will reach a point where professionals in all areas will be aware of FASD and how it manifests itself in our children and young adults. Not all are the same, but there are similar traits that can be followed through on pathways. Base foundations to start from and build upon.

MATERNITY SERVICES - PREGNANT WOMAN WITH FASD

A midwife calling our helpline reported a challenging case with a pregnant woman with mental health and substance misuse issues. The maternity team were working with her but she seemed non-compliant and they were concerned she wasn't prioritising her own health or that of the baby. While the maternity team has had training on the risks of alcohol in pregnancy, they have not had training on how to recognise or work with someone with FASD. It turns out that this woman's dysregulation and behaviours were being misunderstood and misidentified by the maternity team. Once they learned more about FASD they recognised these were signs the woman needed additional support and FASD-informed strategies to support her through her pregnancy and to be a mum. Maternity teams should therefore also have training not only about the risks of alcohol in pregnancy but also about FASD awareness. This is called for in NICE QS 204 but often overlooked by maternity teams.

ORTHOPAEDIC SERVICES PATIENT

We didn't know that alcohol exposure could affect the way the bones and spine developed. Instead over the years it's been a trickle of different discoveries. Before the FASD diagnosis we were told he had some fused ribs. Then, after years of battles in the bath when he wouldn't put his head back to wash out shampoo, we discovered he has fused vertebrae in his neck. We were told then he should never play rugby. By this point he was in gymnastics as a way to channel his excess energy and extreme physicality. The doctors were never clear with us what sort of risk this was to continue, though we figured it was better he learn how to tumble and flip safely as he was doing it anyway (we now understand that was due to sensory needs). After the FASD diagnosis, he was continuing to have problems – his feet are always tingling and the investigations led us to the Royal National Orthopaedic Hospital. It was there that a senior

consultant said this bone damage might be due to prenatal alcohol exposure. But we asked, can't someone please just do a full body scan to tell us where the problems are instead of this constant dribble of information. That didn't happen despite my pleading. Then we discovered that his problems with buttons and tying shoelaces was due to the fact that the bones in one hand hadn't developed properly and he literally couldn't do it. All those years of OT and we had no clue that structurally he couldn't do what we were asking him to do, so he had an amazing operation at Great Ormond Street to move tendons to give him more strength and dexterity (but the recovery freaked him, and he sadly stopped gymnastics out of fear of pain if he put that hand down). Then we found out - more than 6 years after his diagnosis – that an extra cervical rib was trapping an artery. He developed a big bump near his collarbone that he kept hitting to try to break up as he had seen Dr Pimple Popper and thought it was a cyst! We are still waiting for an MRI for this as he will need to be under anaesthesia. He has minor pectus excavatum which seems to be becoming more pronounced as he ages. He is constantly complaining of cold/tingling feet and his feet are having increasingly strange reflex reactions and pain in his heels when he walks. (Doctors have said he has extremely brisk reflexes). I don't believe we yet know the full picture of how his bones have been affected, and no one has said how this might affect him as he ages. Is he more likely to get arthritis? Are there things we should be doing to ensure this doesn't become debilitating over time? Despite all these bone issues, he is not under the care of an orthopaedic specialist at the moment. He'll be 20 soon. If someone with an orthopaedic specialty early on had assessed him head to toe and kept involved with his care that would have helped immensely, including his mental wellbeing so he could understand why he found some things harder, and saved a lot of years of various referrals and wait lists and limbo.

> **We are a specialist orthopaedic Trust with no A&E or Maternity Unit and we wouldn't deal with patients with this disorder.**
>
> -Reply received

MENTAL HEALTH PATIENT AND CARE LEAVER

Y is a young lady who was born in 2002, the youngest of 4 siblings who were taken into care when Y was 15 months old. At that time her mother was unable to parent her. Y was nonverbal and was not meeting any of her developmental milestones. Her foster carers who later became her guardians were every experienced in trauma informed practice and supporting those with unmet attachment needs and yet were not making the developmental difference that they or those in the teams around Y were expecting. There were a range of services involved in her life including community paediatrics and CAMHS who also had a limited impact on her life.

Things began to make sense when she eventually was diagnosed with ARND (now FASD without sentinel facial features), ASD & ADHD in 2016 at the National FASD Clinic in Surrey. She was fortunate that her assessment was funded under the exceptional funding protocol for the area where she lived which allowed the specialist teams at the National Clinic to make the varied assessments required for a full diagnosis. Clearly the early life experiences that she suffered have also had an impact and she is still impacted from the traumas and anxiety associated with them. Y has always been aware that there are reasons for the behaviours that she displays and the things that she thinks.

Although she will tell you that she didn't really get it until quite recently.

School wasn't always easy for Y, and she became subject of an Education Health and Care Plan (EHCP). Even so as she was approaching her GCSE examinations at the age of 16, the acquired injuries along side her FASD meant that she was unable to continue with her formal education and she did not take her GCSE's. Her GP and parents each requested support from CAMHS but that did not materialise in a time scale that would have made a difference to her. Fortunately, she was able to gain avocational placement at a college studying small animal care, gaining a level 1 qualification in the first year. The second year lasted 2 days when the college decided to drop the course that she had enrolled on despite it being named on the EHCP. No suitable alternative was offered but, acting on her own initiative she requested and was successful in starting an apprenticeship with then her part-time employer.

COVID and post pandemic has been a difficult time for Y. Anxiety and doubt increased to such an extent that she could not return to complete her apprenticeship or work at all. She attempted to reach out for psychological support that would have been helpful at this point to change her life course, but nothing appropriate was forth coming. At one stage the crisis team did attend after a call to 111, but their support was to talk to her and leave 'worksheets' to be completed, something that at the time Y couldn't do. The crisis team left without a word to her parents where she was living because she was 18, despite being emotionally in single figures. Without any information her parents struggled to support her, and Y couldn't remember what had been said to her.

This meant that her mental health spiralled to the extent that she was taking too many paracetamols in an effort to get someone within the medical system to address her increasing mental health needs. After five of these episodes of this Y realised that rather than helping, medical teams made a judgement that she had capacity to discharge herself in a single moment regardless of her recent medical history, the fact that she had pulled a catheter out of her arm and was bleeding on the floor to get off the ward or the implications of how her FASD impacted her moods and behaviours. Too many times a one-sided discussion with that team by one of her parents about the implications of the co morbidity of mental health issues and FASD was met with a blank look of puzzlement.

So fast forward another three years and Y is much more able to manage, she better understands her conditions and the mental health challenges that she faces. She still isn't working, but she also isn't self-medicating to escape her thoughts and moods. In situations where she is confident and knowledgeable, she can hold her own with anyone, but it still is a bumpy ride. All of this as a difficult struggle without professional interventions that have impacted Y and everyone that she lives with. It's

> **"[Our Trust] provides healthcare for people with serious mental illness, learning disabilities and autism in inpatient and community-based settings. As a mental health trust we do not provide services regarding [FASD]."**
>
> **-Reply received**

not that she doesn't want help for her mental health, it just that so many artificial barriers are in her way.

If it was difficult to get informed professional assessment and support, it's just too difficult as an adult. To look again at her ADHD, diagnosed as a child, she needs a reassessment as an adult, but she is told that the waiting time is nearly 2 years. Many, many months to reinforce the perception that no one cares and allow her mental health to spiral down. Of course, there is the option of applying for a virtual online assessment where the waiting lists are shorter, but still too long, but that requires retelling a harrowing life story online without prompts, deciding what is important to say when you can't differentiate from everything that is in your head and even remembering a password to access the platform As a patient she sees her life and 'conditions' wholistically so thinking that addressing ADHD is just one of the issues she faces and the rest is being ignored doesn't help Y.

IMAGING DEPARTMENTS PATIENT

There were several times when my son needed imaging but the people doing the images had no understanding of FASD and did not show the flexibility needed to support him to have the needed investigations. He's never received visuals to show him what will happen for example.

At one point his treatment was set back because he needed an x-ray and the technician was trying to force this tiny kid into an adult's gown. I begged that he be allowed to wear his tshirt or go bare chested and the technician refused. We had to leave, he was in full meltdown needlessly and it took us years to be able to convince him to have an x-ray again. I am sure that person didn't understand our child's FASD, didn't understand how hard it was to process – but they should have been trained at least to understand neurodevelopmental conditions.

MRIs have been a constant problem. Once when he was little he had one while sedated. But as he has grown older there have been several investigations that have been delayed or haven't progressed because of this. We have asked if they need to do it, can they not combine MRIs and sedate him once and do the MRI of his heart, ribs/arteries, and now optic nerve all in one go. Over years the issue of an MRI for his pale optic nerve keep getting delayed and we are concerned there may be an issue with his eyesight – and his future eyesight - that is not being properly understood.

Now that he's progressed into adult services we keep getting told that's not possible at such-and-such hospital. Meanwhile, these important investigations aren't happening and we don't know what impact this is having on his long-term health. I don't think anyone understands how hard it is just simply to get our son to appointments, let alone to hospitals hours away for procedures he doesn't understand. Joined up thinking across services would help so much. His care is complex and all of these individual appointments and follow ups are impossible for him to understand or follow. No one doctor is overseeing this and things are getting forgotten or lost in the system with who knows what impact on his future health.

AMBULANCE AND A&E PATIENT

My young person's experience of the ambulance services weren't very good. They definitely didn't understand his FASD and he needed the ambulance service a lot as a young adult. When he fell from a great height the ambulance took him to hospital. When I got there, a nurse took me into a separate room and asked me if he had special needs. "It's just when we ask him questions he seems confused and we can't tell if that's concussion or a learning disability, it's just very odd ". I said that we were awaiting a diagnosis - but I thought it was FASD. They hadn't a clue what that was! He was later diagnosed with FASD. Other times he just refused to go to the hospital. The paramedics would be concerned about his heart rhythm and he'd refuse to go - so they'd just let him go. They needed training in FASD. They found him perplexing!

NEUROLOGY PATIENT

This journey has been one of branches of my daughter's diagnoses that we thought would be the easiest, but nearly 12 years later we are still no closer to any answers and have never encountered anyone in neurological services who understands FASD.

After R's psychotic breakdown at age 10, I started noticing what occasionally she eyes were not focussing and she was not aware of where she was when she regained focus. It was only me that was noticing them. I started to question myself that they were actually happening as they were only lasting not even a second. I was explaining them to her teacher as I had noticed the episodes were getting longer and more frequent, she said she hadn't notice anything but a TA who was listening said that she hadn't noticed them but Rachel's best friend at the time would sometimes ask Rachel, where had she gone. After speaking to the friend it was clear she was seeing what I saw.

The GP asked me to video the episodes, but this was really hard as I never knew when they were going to happen and they were so quick. As Rachel had other conditions that were impacting her everyday life, the episodes were always played down as it was only me and friend that noticed them.

As years passed the episodes got more frequent and were lasting longer. More people were starting to notice them, but again they weren't high on the GPs priority list of her conditions. Until one Sunday, where she just started to have episode after episode, like every second she eyes were rolling and when she came to focus she couldn't remember what she had been saying etc. The on-call GP said to call an ambulance. She arrived at A&E with the episodes still continuing. The triage nurses couldn't make sense of them, but as her vital signs were all ok they said she would have to go to urgent care. With every episode Rachel was getting tired. By the time she was seen by Dr they were happening every 2 minutes and she just wanted to sleep. They sent her home and said a neurologist would contact us.

We had an outpatients appt with neurologist who knew nothing about FASD but sent her for EEGs. The results showed she was having seizures but they were not sure what was causing them. So we were sent to Kings College Hospital for further tests. She had lots of EEG type tests plus sleep ones. The results were she was having 3 different types of seizures , only one COULD be linked to epilepsy. They tried her on 2 different types of medication but due to her FASD she had bad side effects and had to be taken off them.

So today we just monitor now, she continues to have bad days where she will have episodes all day and the episodes are getting longer but for the time being will still have no real answers or treatment, and have not seen a neurologist who can help manage her care, who can help her understand how this unusual presentation might link to her FASD and what the impact might be as she grows older.

> **[W]e do not hold the information you have requested as NICE QS 204 is not applicable for our Trust.**
>
> **-Reply received from a leading neurology hospital**

A&E AND CARDIOLOGY PATIENT TRANSITIONING TO ADULT SERVICES

"So, what is this acronym F.A.S.D?" This was the question asked of me by the senior doctor at the A&E in March 2024 when we had been referred in for an urgent investigation of a possible heart condition affecting my 16-year-old son. We are fortunate that the GP's surgery where we are

registered is FASD informed. That's largely because one of the senior partners in the practice has personal lived experience of FASD.

Arriving at triage there were no arrangements made that took into account his age (16 and a week) or diagnoses, FASD, ADHD, ASD, Trauma and unmet attachment or the fact that he had been referred by the GP. Therefore, after waiting for 2 hours, we were ushered into a cubicle to speak to a doctor. Her first question was, "so what is this acronym F.A.S.D? There are so many acronyms that mean different things to different people".

Given that the best research that we have in the UK is that between 2% and 4% may be affected by prenatal alcohol exposure and also given that FASD has so many implications for how patients, especially those in crisis will be able to access treatments or respond to questions this is concerning. In our case research undertake in the USA suggests that up to 38% of individuals (with) FASD have congenital heart defects, then an informed practitioner may have had a greater understanding that there may well be significant issues surrounding this referral.

The implication about the lack of knowledge within the multidisciplinary teams surrounding my son multiples the concerns that we have. Chest pains first occurred while playing football in school in September where he had to stop playing and sit in the hall to recover before being supported to his taxi to return home with a bar of chocolate to boost his sugar levels. The school didn't tell us as parents because they assumed that he had recovered. He also had chest pains in December once again playing football this time in an informal kick around with his friends. However, by the time he returned home he had forgotten these pains and didn't make us aware until March when once again he experienced pains and had to be collected from his informal kick around again. As parents that was really the first time that we were able to act.

This also highlights an issue where the NICE Quality Standard is focused on children and young people under the age of 18, but where the service providers consider a patient to be adult at 16. Even if the services for paediatrics had of been of gold standard in our locality, my son was siphoned into an adult assessment pathway where clinicians may not have been trained or familiar with his primary hidden disability and the implications that his has for his care.

At the time of writing the investigations haven't been concluded, specialists from the cardiology team say that although there are issues evident the results are not of typical presentations and therefore further investigations will be needed. And that is fair enough. This too has implications for a young man whose interests primarily revolve around football and the gym and who has his heart set on post-16 study and a care in sport. At the moment as the investigation continues he needs to refrain from strenuous exercise and give this forms the routine and calming strategies that he needs is proving a challenge.

> "[Our] Trust is a specialist cardiothoracic hospital; therefore these questions are not applicable."
>
> -Reply received

MATERNITY SERVICES - PATIENT

I am sharing my experience as a pregnant woman who only discovered my pregnancy at 16 weeks. Fortunately, I do not consume alcohol, so my baby is not at risk of Fetal Alcohol Spectrum Disorder (FASD). However, I find it bewildering that, despite being 32 weeks along and attending several midwife appointments, I have not been asked about my alcohol consumption prior to knowing I was pregnant.

What surprises me is that during these appointments, the focus has been predominantly on other issues. They enquire about smoking habits, experiences of domestic violence, and the state of my mental health—often repeating these questions multiple times during each visit. I have also been welcomed into the midwifery unit by posters about the dangers of tobacco but nothing about alcohol?

I recently explored my pregnancy app, which is a requirement by the trust to access appointments and is full with reading materials endorsed by my midwife and other obstetric professionals. I was intrigued to know what information would be available about the harm of alcohol on unborn babies too so I used the search feature to look for information on FASD and alcohol. Unsurprisingly, I found nothing. This lack of resources within the trusted app means that if I wanted to educate myself about alcohol's impact on my baby, I must resort to searching on Google—which can sometimes provide inaccurate information.
The saying "knowledge is power" resonates deeply with my current situation and I feel very lucky to have such information; however, it's deeply concerning that such an important topic like alcohol consumption during pregnancy is not adequately addressed in the resources provided by healthcare professionals. Access to accurate information is crucial for making informed decisions and ensuring the health and safety of both myself and my baby and luckily I am one of few who has this knowledge to protect my unborn baby – but only through my professional role and nothing through the messages I receive from my healthcare provider, society or education.

PATIENT WITH FASD ON ASD PATHWAY

One family were very surprised in April 2024 to learn that they would now be able to access an assessment for FASD in the area where they lived. For many months they were told that there was not an assessment pathway operating in their locality and they were hitting a brick wall as far as progressing assessment was concerned.

However, their relief and hope were dashed after seeking clarification. The 'FASD assessment' wasn't all that it seemed. The 10-year-old young person is in fact joining a 2-year waiting list to be considered for an Autism assessment. Following a successful diagnosis then 'they will then proceed with other tests to establish FASD'. However, no one was able to explain what these 'other tests' might be, when and where they would happen. So effectively this family feels that they are now on a waiting list, but assessment for FASD, the condition that medical professionals believe is likely to be presenting, is still no closer.

Not only does this clearly demonstrate a lack of understanding of the diagnostic protocols for FASD within the Integrated Care Board, but also demonstrates a lack of commitment to appropriately addressing the needs of children and young people who may have FASD as set out in the Quality Standard. The family is distressed – they and others believe no one who may have FASD should be placed at the end of a waiting list for a totally different condition in the hope that they will clear that hurdle and that at some point in the future they might be fortunate enough for the services to then recognise the impact of prenatal alcohol exposure so that their primary health condition and needs are recognised. These are precious years in the life of a young person who has needs that are not fully identified and addressed.

The NICE FASD Quality Standard 204 was specifically written to ensure that anyone who may have FASD would be able to assess an informed assessment pathway to identify FASD, not that they would be placed at the ends of waiting lists for co-morbid conditions. SIGN 156 (upon which NICE QS 204 is based) states that prenatal alcohol exposure should be 'actively considered' as a cause for neurodevelopmental delay, not that it should be the last consideration. Yet this is still the approach that is clearly being adopted in some Integrated Care Services.

ADULT PATIENT WITH FASD BEING PLACED INAPPROPRIATELY INTO ALCOHOL SERVICES

P is a 22-year-old former foster child who was diagnosed with FASD in her early teens. As a young adult attempting to make her way in the world the lack of pathways for and professional awareness of FASD is making that journey far harder than it should ever be. She is facing barriers caused by ignorance of FASD in every aspect of her life and this is taking a toll on her. This is a huge waste of effort and expense on everyone's part and a waste of P's potential.

In education, she has had her EHCP withdrawn because she no longer was engaging with education. She couldn't engage with the vocational course that she was studying without direct help to organise herself and her day. That support wasn't included in her EHCP and therefore she struggled to meet deadlines or to be in the right place at the right time.

She is currently unemployed and is meant to be receiving support to find employment. However, the organisations supporting her don't understand the impact of her FASD and therefore she cannot meet the expectations that they have of her. P was meant to be supported by the Intensive Personalized Employment Support programme in her local area. This gives assistance 'to individuals with disabilities and complex barriers to work'. The staff, who statistically are likely to be supporting hundreds of people with diagnosed or undiagnosed FASD, showed a total lack of understanding of the condition. They only focused on the word 'alcohol' from Fetal Alcohol Spectrum Disorder and routed her onto a programme for supporting people with their alcohol use with the aim of stopping drinking so that she could be fit to access the workplace, which is not the support she needs or deserves and highly confusing for her.

P hasn't had access to local support to help her understand her condition and come to terms with how she is affected. She can no longer volunteer in her local hospital, something arranged to help her develop workplace skills. She has been told she cannot go back because she "over shared" with staff about her FASD.

Her learning disability nurse told her that they do not know what FASD is, but said P should just try harder to fit in with the support that has been offered.

P needs a management plan, as called for in NICE QS 204 Statement 5, co-ordinated by people who understand her and her FASD, not by people who latch on to a single word and / or assume that solutions are readily available that have been successful working with other people with different conditions. P says she feels 'sad to think that people don't know about us (people with FASD)'. She goes on to say that 'we feel exhausted and tired of trying to explain ourselves over and over again. We feel like we are almost invisible'.

> **We feel like we are almost invisible.**
>
> -22-year old with FASD

ADULT PATIENT WITH POSSIBLE FASD SEEKING DIAGNOSIS

In the past year, an adopted adult with a history of prenatal alcohol exposure, who lives in an area with no pathway for adult diagnosis of FASD, had asked to be referred to the FASD Clinic in Surrey. As part of the referral the individual needed to have genetic testing to rule out any genetic cause of the presenting difficulties. They were laughed at by their GP who said "FAS is diagnosed when a woman is pregnant, not in adults". This demonstrates how both a lack of diagnostic pathway and a lack of training for healthcare practitioners are creating a barrier to diagnosis and support.

ADULT SOCIAL SERVICE USER UNABLE TO ACCESS DIAGNOSTIC SERVICES WITH TRAGIC IMPACT

A was known to social care as a vulnerable young adult with FASD, but his diagnosis had not included a neurodevelopment assessment. At the urging of his former foster carer, the social worker (who had no FASD training) had been liaising with an FASD expert, who emphasised how crucial the neurodevelopmental assessment would be to understand A's functional ability and needs. However, when his social worker tried to arrange these assessments, all the doors were closed. They contacted the learning disability team who said, "It's not us" because A's IQ was over 70. They contacted the community mental health team who also said, "It's not us." The social worker went round and round in circles failing to get anybody to conduct the assessments while the young person's mental and physical health spiralled ultimately resulting in his death.

LOCAL AREAS TAKING ACTION

We present in-depth information about some area's actions in relation to NICE QS 204 at length in hopes that it will inspire other ICBs who do not consider responding to NICE Quality Standard 204 to be the responsibility of ICBs to reconsider their role. ICB engagement sets the tone in providing impetus for systemic improvements in the quality of care, including via policy setting, funding and commissioning of services. Equally, we provide some examples as well to show that sometimes other parts of the system can serve as the catalyst to encourage broader systemic change.

NHS GREATER MANCHESTER ICB

Greater Manchester stands out as an ICB that is prioritising NICE Quality Standard 204.[43]

Greater Manchester ICB are proactively ensuring that multi-sector services are aware of the kinds of improvements called for in the Quality Standard and they are embedding this work in key planning documents.

Full implementation of the standard is a specific priority within the NHS Greater Manchester (GM) Joint Forward Plan, which states that GM will "Build on our activity to date on tackling the harms associated with alcohol consumption in pregnancy by fully implementing the NICE Quality Standards for Foetal Alcohol Spectrum Disorder (FASD)". The plan includes a hyperlink to the Quality Standard.

The Quality Standard has been presented to:

- The Children and Young People's Wellbeing Board,
- The School Readiness Board,
- The Maternity Programme Board,
- The Greater Manchester Population Health Team,
- The Drug and Alcohol Commissioners meeting,
- GM Public Health Leadership Group and
- The Clinical Effectiveness and Governance Meeting for wider distribution.

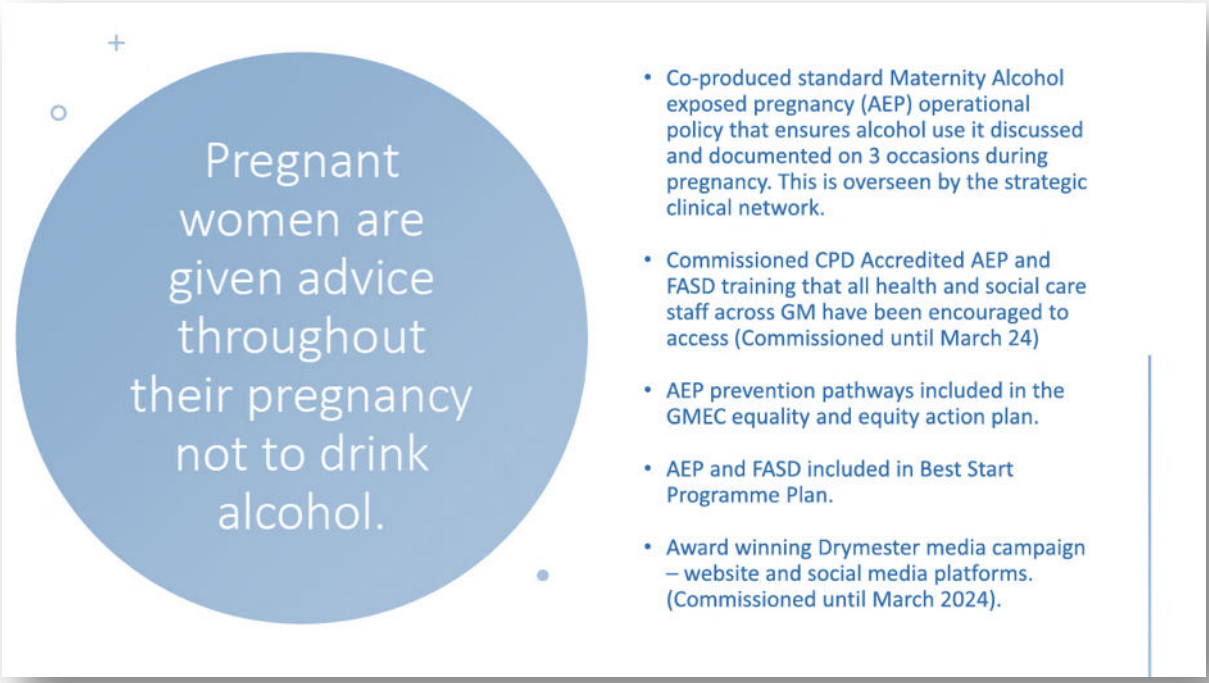
"The standard is presented as part of a commissioned training programme delivered to health and social care staff, carers and families, police, adoption and foster staff, drug, and alcohol staff and primary care across GM. In the 2 years since the publication of the standards 26 virtual training sessions and 2 face to face sessions have been delivered to over 2000 participants…."

"Overall leadership sits with the NHS GM Population Health Committee, but responsibility for delivery is more dispersed. Day to day operational leadership is provided by a Strategic Lead for Population Health. Statements 1 and 2 - monitoring the implementation of the Alcohol exposed pregnancy standard operational policy (SOP); Strategic Lead – Population Health; Statements 3 - 5 - Early years and school readiness board. Strategic Lead – Population Health."

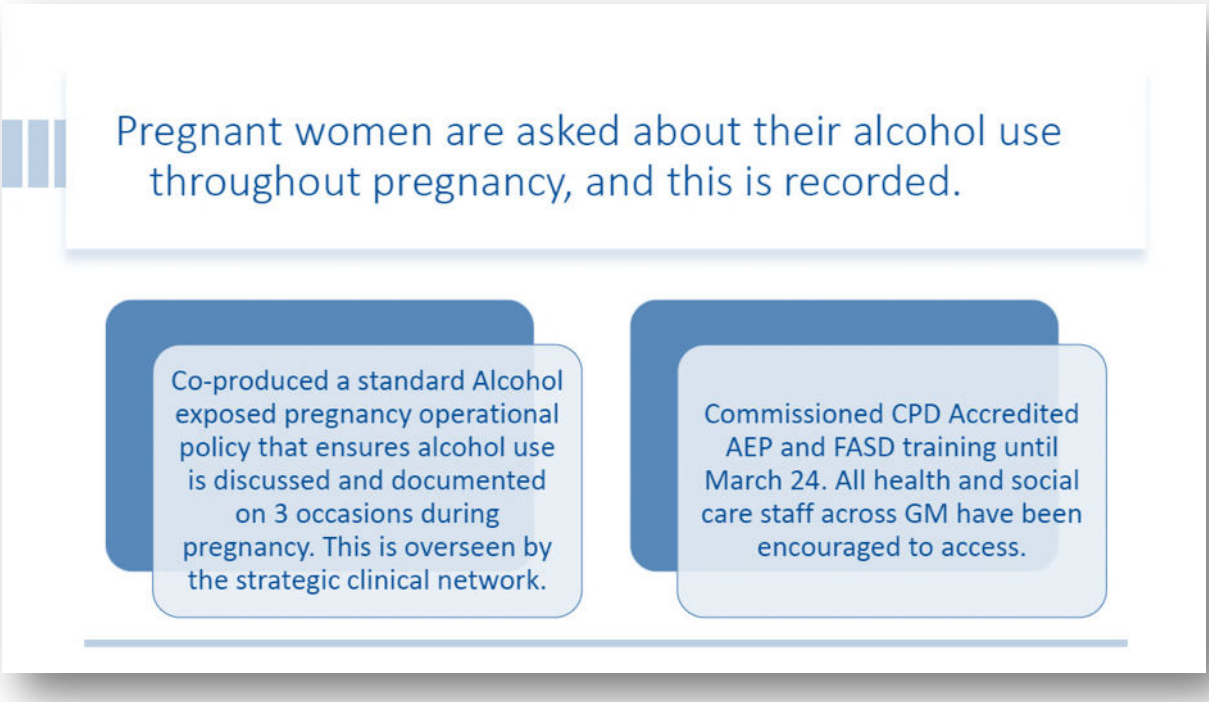
While their response is not perfect (the slides below note some areas where they have yet to take action, including the lack of a diagnostic pathway and little attention at the moment regarding adults with FASD), it is without doubt that the GM ICB has taken on board NICE QS 204 and is seeking to improve quality of care for some of its most vulnerable

[43] This section draws from the GM ICB response below, please see their response for more information, as well as from an undated PowerPoint presention, Fetal Alcohol Spectrum Disorder, QS 204 15 March 2022, A Greater Manchester response, provided to National FASD 30 April 2024. Please note: National FASD is current under contract with the GM ICB to facilitate improvements in the Greater Manchester FASD Network.

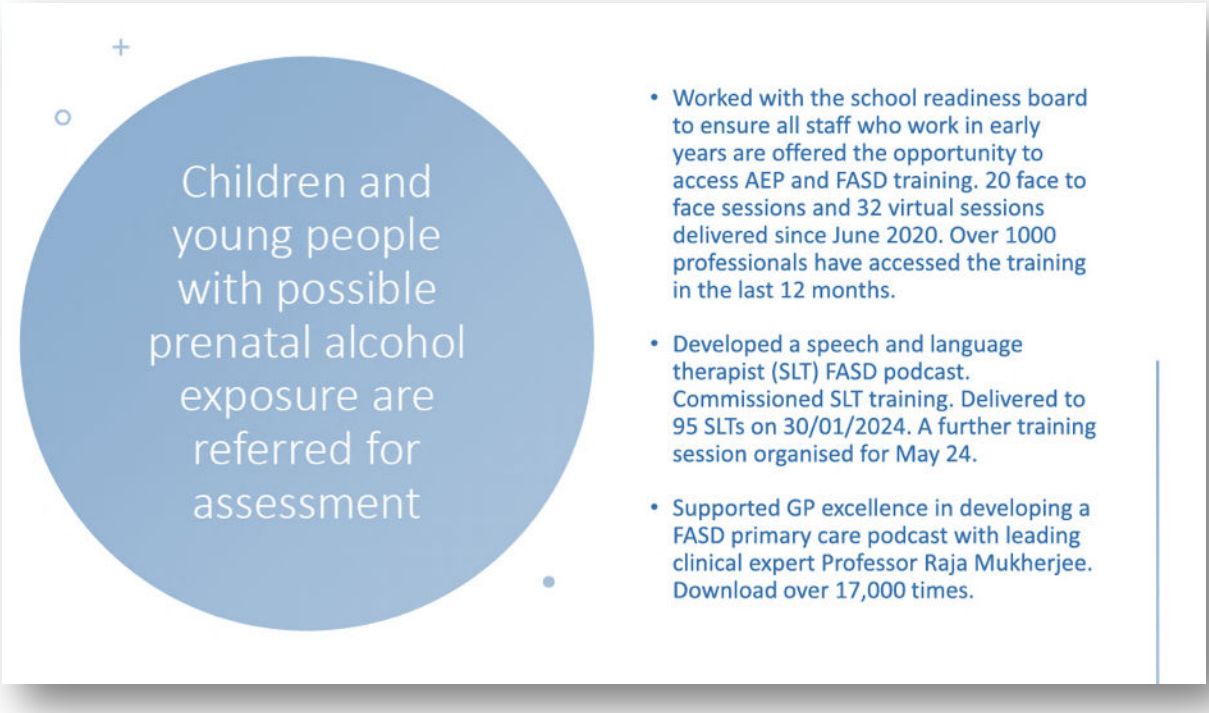
GM ICB Response to NICE QS 204 Statement 1:



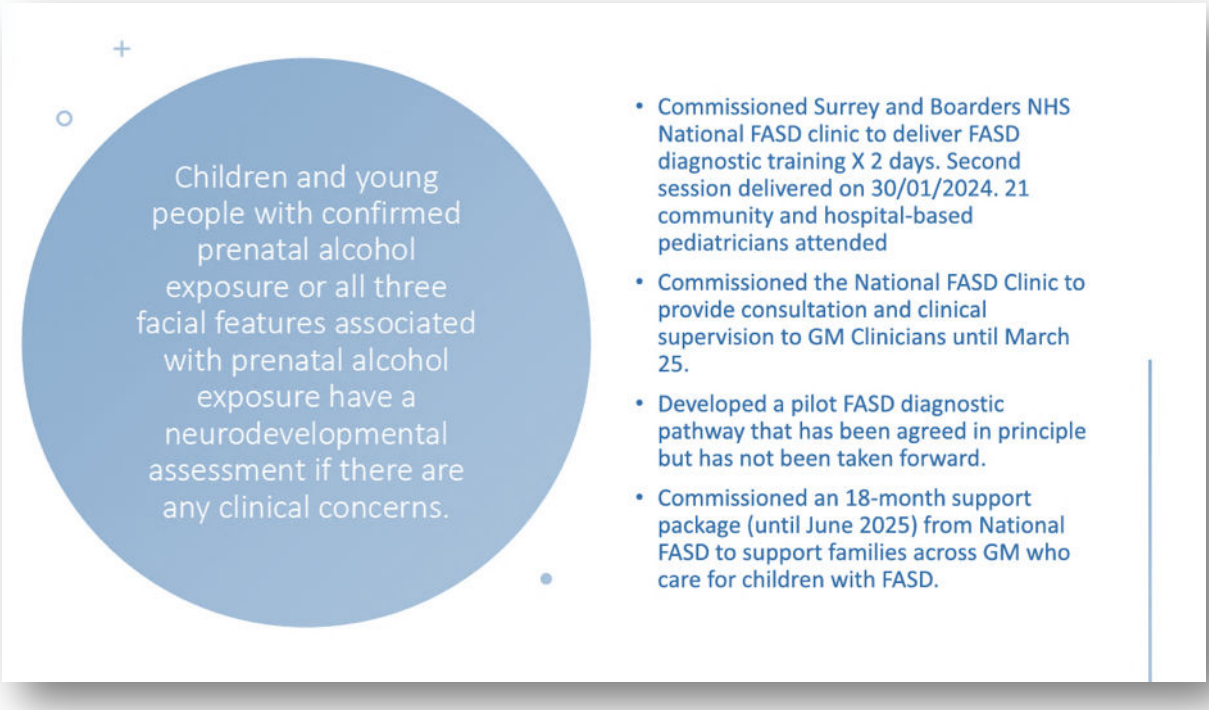
GM ICB Response to NICE QS 204 Statement 2:



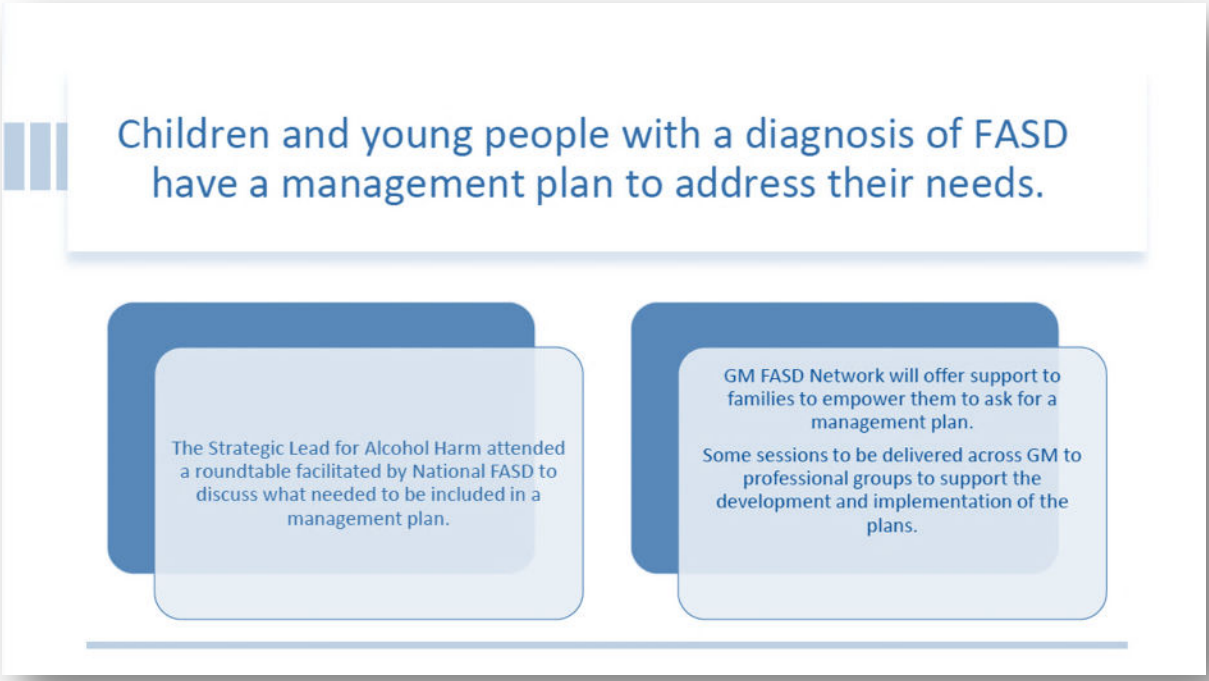
GM ICB Response to NICE QS 204 Statement 3:

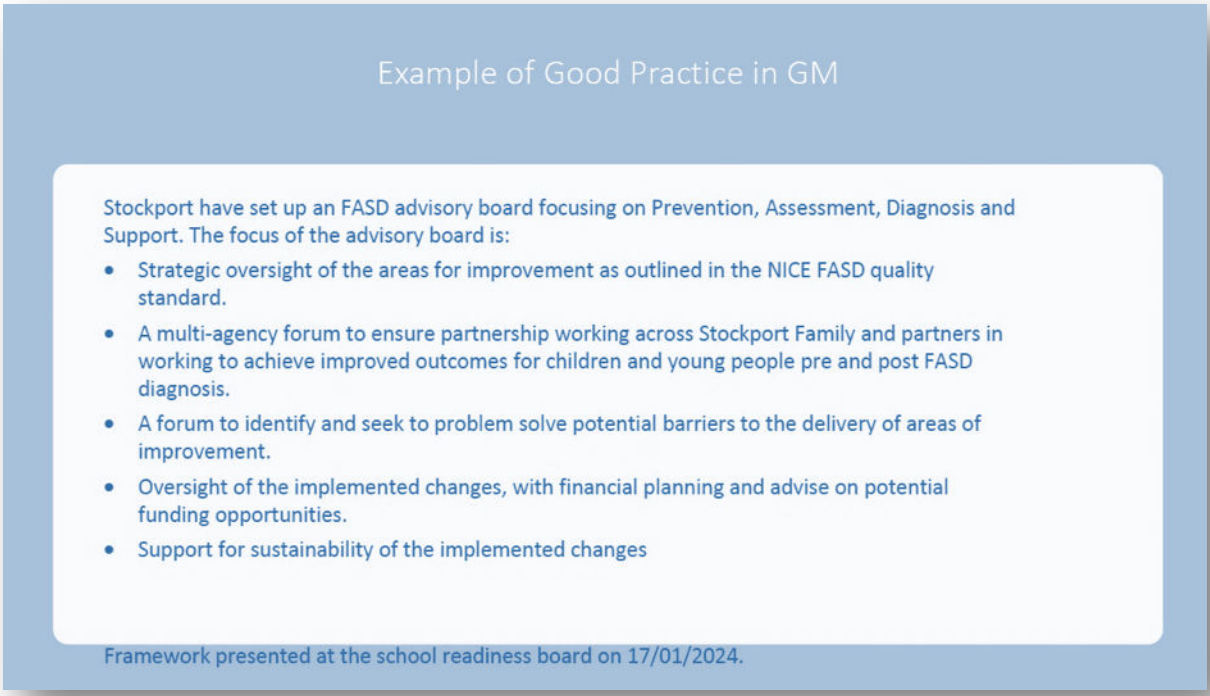


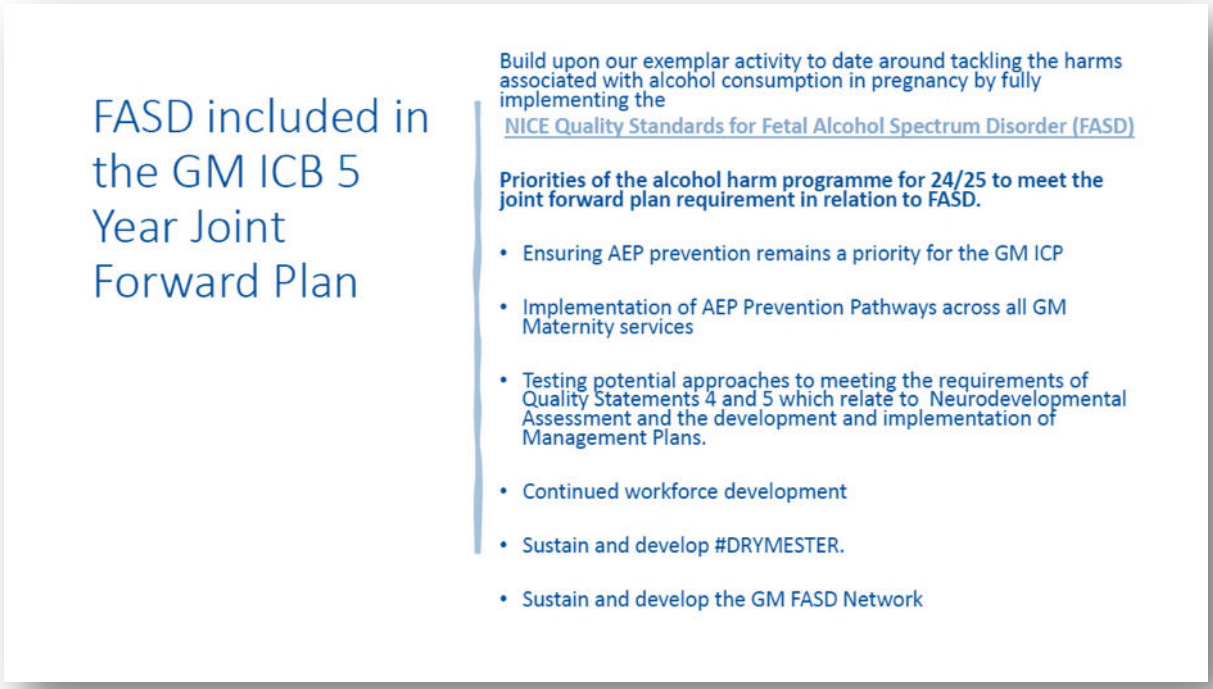
GM ICB Response to NICE QS 204 Statement 4:

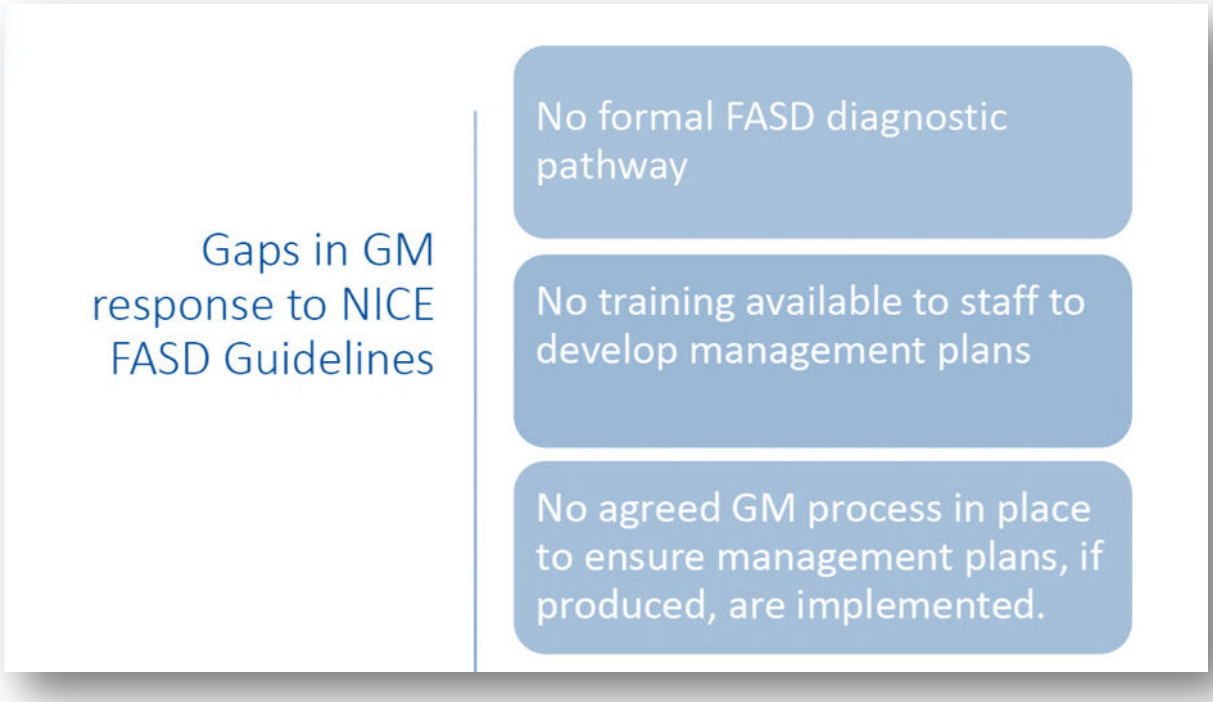


GM ICB Response to NICE QS 204 Statement 5:

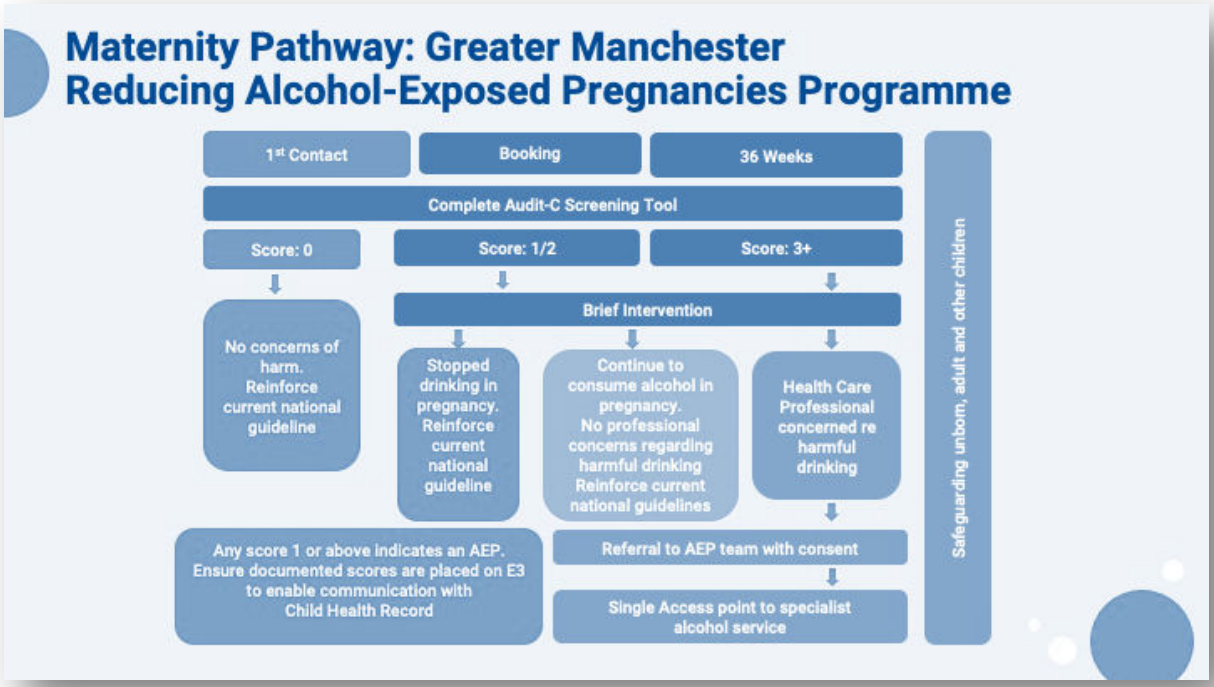








Source: Strategic Lead for Population Health, Greater Manchester



(Source: *The Time is Now*)

HACKNEY

Hackney stands out as an area where an elected official has taken leadership on FASD and in partnership with others has begun to initiate change. Hackney's response to NICE QS 204 is not as far along as some other areas but it is building its response solidly. Hackney started by conducting a scoping exercise led by a public health registrar with former experience with FASD, and they have an audit underway. They have identified a local FASD lead. The interest of the then-Speaker of the Council helped bring together a wide range of people across sectors.

They conducted interviews with various stakeholders involved in the diagnosis, management, and support of people living with FASD with the aim of comparing current practices in Hackney with current NICE Quality Standards. They spoke to:

1. Senior Clinician, Turning Point UK (City and Hackney drugs and alcohol recovery service)
2. Service Manager, Turning Point UK
3. Clinical Lead, Homerton Hospital Alcohol Care Team
4. Lead, Perinatal Mental Health Team + Health Visiting
5. Senior Midwives, Public Health and Safeguarding Team

The Speaker of Hackney convened an event held in the Hackney Service Centre on 11th September 2023 (to commemorate international FASD Awareness Day on 9/9) involving keynote speakers from public health, drug and alcohol care teams, local government, as well as parents and children living with FASD. Turning Point ran a multidisciplinary teaching session about perinatal addiction in 2022, and aim to schedule further sessions specific to FASD and alcohol in the future.

They have identified the management plan at present "remains to be a long-term goal due to the lack of local diagnosis and referral pathways for FASD, as well as data regarding the incidence of confirmed FASD

among people living in Hackney. However, with regard to developmental and social support, structures and programmes are already present in the borough".

Cllr Anya Sizer, then-Speaker of the London Borough of Hackney said, "As an elected official but also as the parent of a child with FASD, I firmly believe it is imperative that this issue is raised, addressed and acted upon both locally and nationally. As Speaker of the London Borough of Hackney I hosted our first ever FASD event in the town hall which included a wide range of stakeholders and interested parties. The attendance was overwhelming and highlighted just why this event was so needed. From that we have as a borough committed to ongoing analysis and action to support the many families that are affected locally. From raising awareness of the effects of alcohol and prenatal exposure to diagnosis and then working collectively on better pathways for those impacted. There is much work to be done and more awareness needed but I know with a prevalence exceeding that of Autism we urgently need to address this issue. I am hopeful that Hackney can encourage other boroughs and other elected officials to see the need and act upon it for the sake of the thousands of families affected."

SHEFFIELD

In Sheffield the response to the NICE QS 204 originated outside the NHS, with the Children's Safeguarding Partnership, which ultimately set up a cross-sector All Age FASD Steering Group. This group is multi-sector and is ensuring all key stakeholders are aware of NICE QS 204 and needed improvements. The Director of Public Health has been involved in the work.

In addition to the work outlined below, they also now have a maternity FASD meeting to help improve Midwifery, 0-19 and GP communication relating to FASD. The Sheffield Children's Foundation Trust also have asked all their services – 0-19, CAMHS, Children's Hospital, etc - to develop responses in relation to NICE compliancy for FASD.

FASD delivery plan – NICE Quality Standards - main activities and milestones 2023/24

Leads – All Age FASD Steering Group

Statement 1 - Pregnant women are given advice throughout pregnancy not to drink alcohol. (including pre-pregnancy prevention)			
Actions to be taken	**Leads**	**Measurable Outcome**	**RAG**
Professionals are confident to ask pregnant women about alcohol use and discuss FASD		FASD training – part 1 and part 2 attended by all professionals. Routine questions asked by all professionals – accurate and non-blaming.	
The public recognise the importance of not drinking alcohol when pregnant		Prevention posters and leaflets displayed widely. Pubs and clubs displaying resources regarding not drinking when pregnant – Beermats in pubs South Yorkshire digital campaign Club soda campaign – free soft drink for pregnant women	-
Discussion about FASD part of RSE lessons in schools and alternative provisions		Resources and videos available to schools FASD incorporated in Health and Wellbeing resource for schools. Vulnerable Adolescent Team running groups for girls – including risk of drinking alcohol when pregnant. Youth clubs promoting no alcohol no risk message	-
Dangers of drinking alcohol in pregnancy incorporated into health campaigns in university and colleges.		Health centres in University and Colleges displaying FASD materials. Midwifery and health courses including discussion regarding FASD	-
FASD prevention message being delivered to vulnerable groups. No safe time, No safe amount, No safe type		Substance misuse workers discussing FASD with service users to spread the word within the substance misusing community. FASD resources on display. Refuges displaying FASD resources. Sexual health services and services supporting sex workers display FASD resources. Perinatal mental health services having the discussion	-
FASD Prevention posters displayed across the city		Maternity Hospital, Northern General Hospital, Statutory services, Substance misuse services, Train station, Sheffield Markets, Library, Fertility clinics, Family Hubs, Private Health settings, pharmacies	-
FASD prevention in newsletters		South Yorkshire Pharmacies, SEND, SCSP	-
Write to your MP campaign		Letter written and been sent to MP's regarding discussing in House of Commons FASD prevention and support	-
			-
Other comments / Issues: Supermarkets, Pharmacies, Gyms, and Sport clubs encouraged to display posters, leaflets / play videos			-

Statement 2 - Pregnant women are asked about their alcohol use throughout their pregnancy, and this is recorded.			
Actions to be taken	**Leads**	**Measurable Outcome**	**RAG**
Midwives are confident to ask pregnant women about alcohol use and discuss FASD		FASD part of midwifery mandatory training Maternity hospital IT system being updated to capture alcohol consumption during pregnancy and prompt CMW's to ask the question and give the advice at every antenatal visit FASD leaflets included in all pregnant women booking records and used for discussion by CMW	
Alcohol use during pregnancy recorded in records by all professionals		Alcohol use during pregnancy part of 0-19 discussion with parents – including antenatal visit. Discussed in Perinatal mental health appointments pre and post-natal. FASD READ codes used in health records. Alcohol queries incorporated in antenatal templates for GP records. MAPLAG meeting discuss alcohol consumption in pregnancy. Paediatric liaison records in baby's notes.	-
Language professionals use when discussing alcohol use during pregnancy		Consideration of the language that social workers and other professionals can use when discussing alcohol use during pregnancy – non blaming and accurate / up to date. Part of new workers induction	-
			-
Other comments / issues: GP's discussion at 8 weeks appointment, Support for parents who decide to continue to drink or were unaware of the harm alcohol can cause			

Statement 3 - Children and young people with probable prenatal alcohol exposure and significant physical, developmental, or behavioural difficulties are referred for assessment.			
Actions to be taken	**Leads**	**Measurable Outcome**	**RAG**
Children and adult medical professionals trained to recognise and where possible diagnose FASD		CAMHS and Adult Mental health services have all received training from Professor Raja Mukherjee.	
Prenatal Alcohol Exposure recorded in child's notes		Information in mother's booking records transferred to child's health records. NIPE form / Discharge form / Personal Child Health Record (Red book). GPs receive discharge notes which includes FASD. Discussion included in health visitors check ups MAPLAG meeting discuss alcohol consumption in pregnancy. Paediatric liaison records in baby's notes.	
Referral pathway for children with prenatal alcohol exposure and needing assessment		Small FASD pathway in place Signposting to meet the needs of the children – speech and language etc Service referring into the FASD clinic collect information regarding significant impairments.	

		National FASD clinic providing monthly clinical supervision. Referral form for all neurodevelopment clinics includes Prenatal Alcohol Exposure. All clinicians discuss alcohol consumption during pregnancy with parents	
Philtrum guides in the Children's Hospital		Camera, software, and philtrum guides help to identify children who have FASD facial features	
		Case study to identify barriers / obstacles to assessment	-
Services able to refer for assessment where there was probable or recorded prenatal alcohol exposure		Virtual school having the discussion with the young person FASD considered at Locality Panel meetings	-
			-
Other comments /issues: consideration of the language that social workers and other professionals can use when discussing alcohol use during pregnancy – non blaming and accurate / up to date			

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			
Actions to be taken	**Leads**	**Measurable Outcome**	**RAG**
Prenatal Alcohol Exposure recorded in child's notes		Information in mother's booking records transferred to child's health records. NIPE form / Discharge form / Personal Child Health Record (Red book). GP's receive discharge notes which includes FASD. Discussion included in health visitors check ups MAPLAG meeting discuss alcohol consumption in pregnancy. Paediatric liaison records in baby's notes.	
Referral pathway for children with prenatal alcohol exposure and needing assessment		Small FASD pathway in place Signposting to meet the needs of the children – speech and language etc Service referring into the FASD clinic collect information regarding significant impairments. National FASD clinic providing monthly clinical supervision. Referral form for all neurodevelopment clinics includes Prenatal Alcohol Exposure. All clinicians discuss alcohol consumption during pregnancy with parents	
Babies identified at birth as at risk of FASD have specialist follow up – offered by neonatology.		Follow up clinic by neonatologists for all women discussed in MAPLAG	
			-
Other comments / issues: transitions			

Statement 5 Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs			
Actions to be taken	**Leads**	**Measurable Outcome**	**RAG**
Fully holistic care management plans that cut across all sectors for children, young people in transition and adults.		Developing a care management plan template. Consideration for which service/ lead professional to support the management plan and ensure assessment updated at significant transition points / planned intervals	
Parent and carers forum includes supporting those who care for young people with FASD.		Together with families with lived experience develop FASD resource packs for individuals and families. Incorporate strategies for supporting people with FASD into parenting programmes.	-
Children's social care legal gateway meetings considers FASD in parents		FASD sheet written for inclusion in notes for Legal Gateway	-
Parent Assess (assessment for social workers to use with parents who have neurodevelopment issues) to include FASD		Discussion with Parent Assess developer. General agreement received that FASD will be consider and added to assessment form	-
FASD police Alert cards		Developing the Alert cards to include FASD alongside Autism and ADHD	-
School environment suitable for people with FASD		Work with SENCOs, and the Inclusion Taskforce to identify school needs - resources, support, and strategies. 2 x Me and My FASD course held in Sheffield	-
Education for the Criminal Justice system		FASD and Criminal Justice conference planned for April 2024 – for police, probation, youth justice, YAS, Liaison and Diversion, Appropriate adults, defence solicitors, and Crown Court FASD sheet written to include with pre-sentence reports	-
			-
Other comments / issues: CP attending All Age Steering Group in July 2024			-

Source: Sheffield Children's Safeguarding Partnership

ALDER HEY CHILDREN'S NHS TRUST

Alder Hey's Children's NHS Trust's response[44] included a position statement on FASD that could serve as a model. They have a "Beyond FASD" steering group and have conducted some scoping work and internal audits and included FASD in a hospital-wide grand round.

We are highlighting this response as their document goes through the Statements in NICE QS 204, using the indicators and identifies action points. For example:

[44] To see the full response please go to: https://www.whatdotheyknow.com/request/trust_response_to_nice_quality_s_2#outgoing-1602218

<table>
<tr><th colspan="2">Alder Hey</th></tr>
<tr><td>Statement 3:

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.
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.
b) Evidence of local arrangements to increase awareness of FASD among healthcare professionals
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 Paediatric service for a number of years.</td><td>Statement 3 actions to be taken:
Internal referrals:
All children being assessed or diagnosed for FASD should be coded on trust electronic systems.- to be discussed.
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.
There should be a presentation regarding the SIGN and NICE guidelines in Grand Round which is hospital wide teaching- completed.
External referrals
Once there is a dedicated service, this will be communicated with social care, primary care and education.
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</td></tr>
<tr><td>Statement 4
Evidence of local services with healthcare professionals with expertise in neurodevelopmental assessment who have had additional training in FASD.
There is no pathway for referral outside of a standard referral to the developmental paediatric department.</td><td>Statement 4 actions to be taken:
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.</td></tr>
</table>

• Some clinicians have done additional training through the RCPCH, NOFAS-UK [National FASD] and study days. • There were 3 consecutive weeks in departmental medical teaching in 2020 around FASD. • A number of staff have attended or completed online FASD courses. • Training for FASD is incorporated in the induction talk for looked after given to every new registrar and staff grade. *Diagnosis rate for FASD* There is an audit currently underway for comorbid conditions such as ASD and FASD in the ADHD population.	• There should be a training/awareness package for FASD for new registrars but available to the rest of the trust. • 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. • - currently on hold until clarity on service provision • Trust guideline for the assessment of FASD • 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. • Ideally there needs to be the development of a unifying streamlined service looking at all areas for FASD. • -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.
Statement 5 *Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations.* • 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	**Statement 5: Actions to be taken:** • Awareness of FASD via liaison with ICB Designated Doctors and Nurses for Looked After Children regarding training for outside agencies. • Training regarding “Care Aims” reports to improve plans for children.

they use the SIGN guidance. 57% stated they were unable to coordinate care and assessments across disciplines. *Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services.* • Only one respondent to the survey stated the child had received a SMART plan. • All letters are copied to school, school nurses and social worker ifinvolved. 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 for in area children are kept up to date on EPR.	

SOUTH TYNESIDE AND SUNDERLAND

This Trust also is using NICE QS 204 indicators and provided the following table tracking the indicators. We also note they have and FASD task and finish group and are seeking to work regionally as well. (However, without evidence of training for maternity teams on how to have these conversations, the number provided for rate of alcohol exposed pregnancies appears quite low compared to statistics that show greater than 40% of pregnancies are alcohol-exposed in the UK.)

Quality Statement 1:				
Advice on avoiding alcohol in pregnancy				
Structure:	Process:	Local service:	Outcome:	**Result:**
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.	Proportion of antenatal appointments in which pregnant women are advised not to drink alcohol during pregnancy	98%	Rate of alcohol-exposed pregnancies	**10 of 2216 (0.5%)**
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 on alcohol consumption in pregnancy.				

Quality Statement 2:					
Documentation of foetal alcohol exposure					
Structure:	Process:	Local service	Outcome:		**Result:**
Evidence of local arrangements to ensure that antenatal appointments include discussion about drinking alcohol in pregnancy	Proportion of antenatal booking appointment where drinking of alcohol is reported	74 of 2216 (3.3%)	Diagnosis rates for FASD		41.60%
	Proportion of routine antenatal appointments in which alcohol consumption is recorded	98%			

Quality Statement 3:				
Referral for assessment				
Structure:	Local service:	Outcome:	**Result:**	
Evidence of local arrangements to increase awareness of FASD among healthcare professionals	No active work within STSFT at present	Average time to diagnosis of FASD	20 weeks from first appointment	
Evidence of local services with healthcare professionals who have additional training in FASD	Yes, FASD assessment clinic as part of neurodis team	Diagnosis rates for FASD	41.60%	
Evidence of local pathways that refer children and young people with probable prenatal alcohol exposure to a healthcare professional with additional training in FASD	Yes, 78 children seen since 2019			

Quality statement 4:				
Neurodevelopmental assessment				
Structure:	Local service:	Outcome:	**Result:**	
Evidence of local services with healthcare professionals with expertise in neurodevelopmental assessment who have additional training in FASD	Yes, FASD assessment clinic as part of neurodis team	Diagnosis rate for FASD	41.60%	

Quality statement 5:						
Documented management plan						
Structure:	Local service:	Process:		Outcome:	Result:	
Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations	No, awaited as part of NENC ICB Neurodevelopmental pathway	Proportion of children and young people diagnosed with FASD who have a management plan	0%	Health-related quality of life for people diagnosed with FASD	? Measure to use	
Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services	No, awaited as part of NENC ICB Neurodevelopmental pathway					

NHS KENT AND MEDWAY

The following response from NHS Kent and Medway highlights some innovative arrangements that are being set up across the country as part of a 'hub and spoke' model. They also have been engaging families in development of the local pathways over years. "NHS Kent and Medway have commissioned a Clinical FASD Support Service from Surrey & Borders Partnership NHS Trust to support Clinicians and other professionals working with children with FASD. This includes diagnostic support, Continuing Professional Development around FASD and support with FASD management and care plans. NHS Kent & Medway have also commissioned a suite of FASD training from an external organisation and this is open to any health, education and care staff across the system. There has also been work with colleagues from Maternity Services and Social Care, including Fostering and Adoption Teams. Prior to NICE Quality Standard 204 being published a there was a Kent & Medway FASD Partnership Group convened. This group included parents and carers as well as professional Clinicians, Social Care staff and Members of the local Councils. The group informed the development of FASD training offers available and developed the commissioned hub and spoke model (Surrey & Borders NHS Partnership Trust)."

OXFORD HEALTH NHS FOUNDATION TRUST

They have sought input from across services as to how NICE QS 204 applies and have identified its relevance to several services. Particularly encouraging is their statement from their Learning Disability Community Service that they will be implementing easy read information on use of alcohol in pregnancy as a result of this review.

CENTRAL AND NORTH WEST LONDON

This Trust provides alcohol and pregnancy guidance in Easy Read format and are undertaking QI work to ensure NICE Quality Standard 204 is available in an Easy Read format.

OXLEAS NHS FOUNDATION TRUST

This Trust is planning to present to stakeholders this year specifically for NICE QS 204.

COMMISSIONING FOR GROWTH - THE HUB AND SPOKE MODEL AND SURREY AND BORDERS PARTNERSHIP NHS TRUST

WHAT IS THE NATIONAL FASD CLINIC IN SURREY?

Surrey and Borders Partnership NHS Foundation Trust has led nationally on FASD since 2009 when Prof Raja Mukherjee established the national FASD Clinic there – a tier 4 National Specialist Assessment Clinic for a Children and Adults, "the only specialist clinic in the UK for assessing children and adults with FASD".[45] It is a very small team that has capacity to see approximately 43 cases per year and has a budget of £220,000. (The clinic also supports local diagnosis via a local agreement within the Trust for 6 Adult and 6 Child Cases to come through to the specialist FASD Clinic when local services in Surrey are unable to diagnose due to the complexity.)

REFERRALS TO SURREY FROM OTHER PARTS OF THE COUNTRY

Several Trusts indicated in their responses that they are relying on referral to the national clinic in Surrey. Quite often an individual funding request to see the team that Prof Raja Mukherjee has assembled is the only opportunity families might have to access diagnosis.

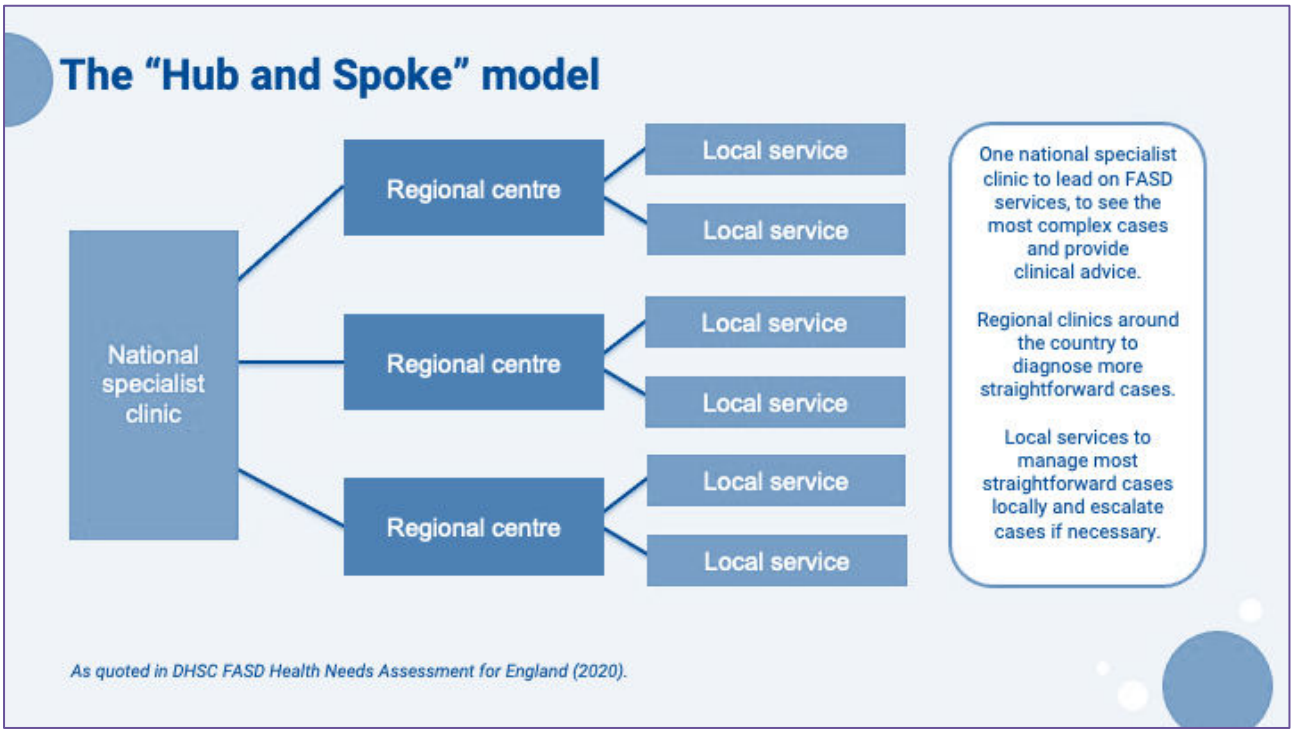
However, for this report's purpose, indicating referral to the national clinic in Surrey is not enough of a response to NICE Quality Standard 204 without additional commissioning in place, either via the Hub and Spoke model or as an interim measure for establishing a local or regional pathway.

As one practitioner said about relying on referrals to Surrey, "Is this sustainable? If waiting times increase will they then commission more local service?" The waiting list for the national clinic is currently 2.5 years, though they hope to reduce this to 18 months.

To help with the demands on local services and to help with ramping up services more cohesively and rapidly, some have proposed a "Hub and Spoke" model that can help clinics needing guidance and support. This is what is being done currently in Surrey and Kent.

> **"Interesting they feel all FASD cases would need to be referred to a national specialist team. Because of the prevalence they should really have local provision for diagnosis with recourse to a national resource if they are unsure of the diagnosis. They must have local facility for diagnosis of autism? Because of prevalence of FASD, referral of all but challenging cases to a national resource is not sustainable. NICE requests provision at local level."**
>
> Senior practitioner reviewing responses that rely solely on IFR to the Surrey clinic

[45] https://www.fasdclinic.com



WHAT IS THE HUB AND SPOKE MODEL AND WHY DOES IT HELP COMMISSIONERS IN OTHER PARTS OF THE COUNTRY?

The Hub and Spoke model is a tiered way to jump-start services on a spend-to-save model:

a. The national clinic leads on FASD services, sees the most complex cases, provides clinical advice
b. Regional clinics around the country diagnose more straightforward cases, perhaps provide peer review
c. Local services manage most cases locally, escalating as needed.

They say, "Where there are clinical concerns relating to FASD, FASD assessment would typically be undertaken by teams without Referral to our specialist Clinic, provided they are aware of the SIGN-156 Guidance, and if they are sufficiently skilled and resourced. As the National Specialist Clinic, we are seeking to train others up in FASD Assessment and develop links locally and nationally in line with the Hub and Spoke model as described in the DHSC FASD Health Needs Assessment for England."

The Clinic addresses NICE QS 204 Statements 3 and 4 but does not meet Statement 5 as it does not provide care management.

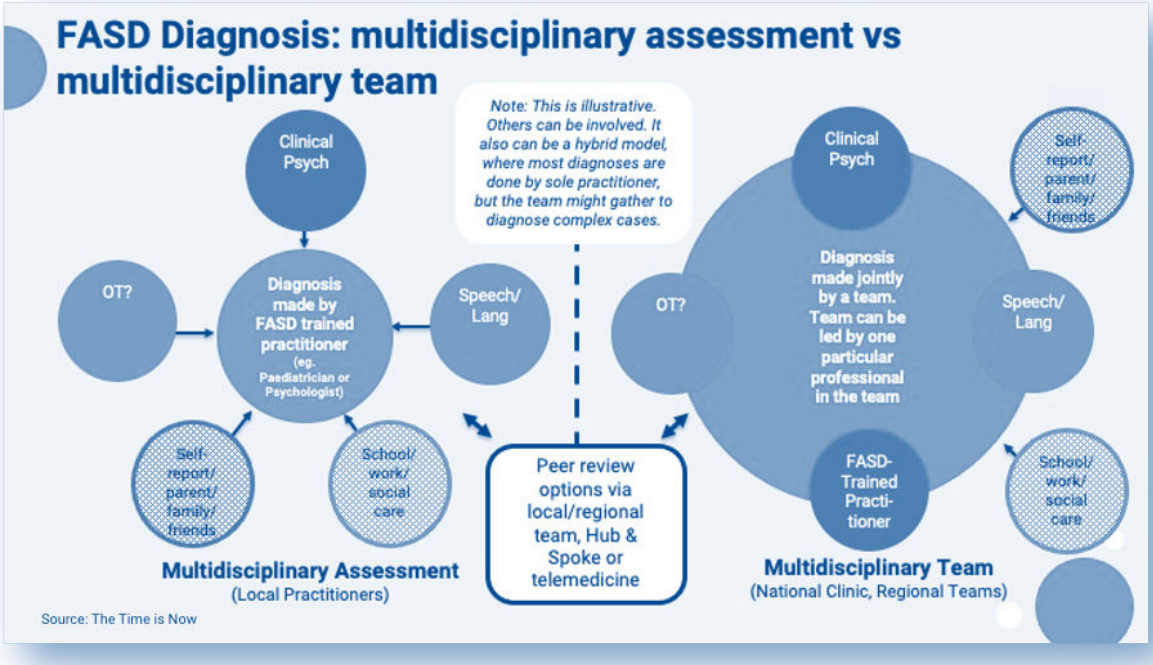
They say, "As the FASD Clinic is currently only funded as an assessment service, we cannot provide ongoing care management. For those seen in the clinic, we write bespoke detailed reports with care management recommendation written in bold in Section 3 of the report for local care teams to implement. We also send a 'What is FASD?' and 'Signposting Support' document. Our Clinical Lead Adult for FASD, FASD Clinic Lead and Neurodevelopmental Specialist Clinician and a parent with lived experience provide a half day online training event post assessment, which outlines what FASD is, the general principles of Care Management and Practical Approaches to Caregivers."[46]

This report indicates the need for NHS England to seed funds on a spend-to-save basis for the national clinic to further develop the Hub and Spoke model

National FASD calls for funding to implement the NHSE FASD Health Needs Assessment

[46] Surrey and Borders Partnership NHS Foundation Trust 11 April 2024 response to the National FASD Freedom of Information request. It did not arrive by the statutory deadline for full inclusion in this report, but it can be found here: https://www.whatdotheyknow.com/r/ae98457d-063f-4ad4-b113-eb74a5f5ae5d?locale=false

recommendation for a Hub and Spoke working model.[47] To achieve this NHS England would seed funds for a time-limited period for a full-time project worker over 5 years, working alongside the national clinic. The goal would be to help England implement the called for changes. They would then be able to help shape and model business cases and establish the networks needed so that after that point in time local areas could take on the processes and embed the processes into their own pathways using where possible an invest-to-save model. This would mean long-term cost savings to the NHS as well as implementing NHSE's own strategy. Others say that ramping up FASD diagnostic capacity does not need the Hub and Spoke Model. They say that it's possible to develop local and regional expertise, so long as there are peer review panels in place that can help build confidence of those new to diagnosis. There are areas such as the North East where this has been ongoing for many years.



[47] See for example, S. Butcher, Supplementary Evidence to Health and Social Care Committee, 6 February 2024. https://committees.parliament.uk/writtenevidence/128459/pdf/

DIFFUSION OF RESPONSIBILITY - EXAMPLES OF THE 'HOT POTATO' EFFECT

Many responses indicated that there is a diffusion of responsibility that leaves people with FASD and their families at a loss as to where to go for diagnosis and management. See for example the indicative responses in the box below. (We do not mean to single these out as exceptions, rather they are indicative of what is happening in many places throughout the country). The ICBs state NICE QS 204 is the responsibility of Trusts, and they mostly appear to have no mechanism in place to follow up on what is happening. The Trusts are not prioritising it because it is not commissioned. We are reminded of the game 'hot potato' where something is considered too hot to handle and is quickly passed to someone else.

BOX: THE 'HOT POTATO' EFFECT

	ICB response	Trust response
Birmingham	The ICB stated clearly in the commissioning response, "No formal FASD service is commissioned. For further information please contact the trusts directly". They said in response to the NICE QS questions, "The ICB board level directed 2024/25 commissioning plan will include consideration of FASD requirements, particularly in relation Community Paediatrics Service provision across the ICS."	Birmingham Community Healthcare NHS Foundation Trust said, "Some diagnoses are given by the community paediatrician however this is challenging due to the lack of a defined pathway and the evidence required from multi-disciplinary team. Children with concerns about possible ADHD/ASD would be referred directly to the ADHD/ASD pathway. FASD may be considered as part of the presentation and assessment however it is not an assessment pathway for FASD specifically and a diagnosis would not be given during this assessment. If there are concerns which might suggest this children can then be referred to community paediatrics for assessment but these would only be seen if fulfilling the remit of our current referral criteria for Community Paediatrics and wouldn't necessarily be seen for FASD assessment specifically if there are no developmental concerns as part of this."
NHS Bristol, North Somerset and South Gloucestershire ICB	The current structure and ways of working in BNSSG ICB means that commissioned providers are responsible for responding to NICE quality standards. BNSSG ICB as an individual organisation is not responding directly to this quality standard.	University Hospitals Bristol and Weston NHS Foundation Trust: The Trust is not commissioned to provide FASD services.
South Yorkshire	The ICB states, "Currently there are no specific services commissioned by NHS South Yorkshire ICB for the diagnosis and management of people with FASD for any age group. We would expect this condition to be picked up through paediatric pathways where the presentation would be related to developmental/ neurodevelopmental delay, and would potentially include genetic testing for other diagnoses etc."	Barnsley Hospital NHS Trust (which has community paediatric services) says, "We do not [have] a pathway or resource for FASD. ICB has not commissioned a pathway for FASD in Barnsley. We do not have a process or the right professionals to assess FASD."

> **Why do they not see the error of this thinking that only allows you to confirm or negate that the person has what they decided to look for in the first place! That's like saying if I'm dizzy and someone looks at whether I have diabetes and I don't, then I can't have a different diagnosis. I despair!**
>
> – Neurodevelopmental Consultant (Retired)

BOX: EXAMPLE OF POSITIVE SYNERGY		
NHS Cambridgeshire & Peterborough ICB	Statement 3 - Neurodevelopmental pathways currently under review – Public services consultancy commissioned by ICB; Statement 4 - Neurodevelopmental pathways currently under review; Statement 5 - Neurodevelopmental pathways currently under review.	Cambridgeshire and Peterborough NHS Foundation Trust is not commissioned to provide services and this was highlighted to the ICB commissioners…[FASD] Not assessed as it is not commissioned.

WHERE DOES RESPONSIBILITY SIT?

> **Standards 3, 4 and 5 are not relevant to the Trust.**
>
> **-Reply from one of the largest and busiest acute hospital trusts in the UK whose services include a children's hospital, children's neurosciences, occupational therapy, speech and language therapy, physiotherapy, autism, ear, nose and throat, endocrinology, genetics, learning disability services and much more**

Responses from across England and Wales also show that responsibility for improvements called for in NICE QS 204 is very much a 'hot potato', even between services within Trusts. Some say responsibility lies within Child Development Centres, some say CAMHS. Some say acute trusts, others say community trusts. But what is missing in too many places is the need for a holistic overview. That is why those areas where the ICB is showing leadership and where proper scoping, audits and steering groups are established are making greater headway.

One can consider the range of various responses below and imagine the confusion families face in trying to navigate the system when compared to the national strategy that exists for Autism and Learning Disability, where keyworkers have been established, pathways are in place and funding backs up the work nationally, including training. The response to FASD needs similar oversight, coordination and funding.

- Central and North West London Trust: "Statement 5… Not CDC as we do not provide interventions. This is for CAMHS, schools, PBS team, social care, early intervention….."
- "Please note that Birmingham and Solihull Mental Health Foundation Trust explicitly provide mental health services and do not provide physical healthcare like an Acute Trust. Your request for information is therefore not applicable to the Trust."
- As a Mental Health and LD Trust, CNTW [Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust] is not commissioned to assess/diagnose Fetal Alcohol Spectrum Disorder, as this would be undertaken by Paediatrics within an 'Acute Trust' NHS setting.
- "Liverpool University Hospitals NHS Foundation Trust is an adult acute hospital and is not commissioned to provide obstetric, maternity, ante-natal, paediatric and Fetal Alcohol Spectrum Disorder (FASD) services."
- "Norfolk and Suffolk NHS Foundation Trust is a Mental Health Trust. It would appear that the questions you have

asked relate to an Acute Hospital rather than a Mental Health Trust."

- Worcestershire Acute Hospitals NHS Trust: "quality standards 3-5 are not applicable to us as an Acute Trust."

- Airedale NHS Foundation Trust: "Currently there is no commissioned service for assessment of children with FASD - and so no local pathways exist."

- NHS Cheshire & Merseyside ICB: "NICE FASD Quality Standard 204 is not specifically considered in decision making about service provision and assessment of local need for learning disability and autism services."

- Tees, Esk and Wear Valleys NHS Foundation Trust – "As a mental health and learning disabilities Trust our role is limited to preventative information sharing, and recognition and referral of suspected FASD. We refer cases of suspected FASD to external Specialists for assessment. We therefore do not include FASD specifically in our patient experience monitoring….Our role is awareness and as such we produced the qualitative baseline assessment, fact sheet and awareness training only. FASD is not commissioned as a stand-alone pathway."

PROGRESS FROM 2019 CRISIS OF COMMISSIONING REPORT TO NOW

National FASD (then NOFAS-UK) issued a report in 2019, "A Crisis of Commissioning: CCGs are Failing Government Policy on FASD"[48]. That report showed:

- None of the CCGs who have provided responses have a policy for commissioning services specifically for Fetal Alcohol Spectrum Disorder.
- Most Trusts said they hold no information on FASD services or do not code post-diagnostic services to record information.
- Only 21.69% of CCGs say they currently provide for the diagnosis of FASD in children.
- Only 8.43% of CCGs say they provide diagnosis for adults and only 4.9% of Trusts say they actually do.
- Just 22 CCGs told NOFAS-UK that they expect the Trusts they commission to provide education and training on FASD. Only 24.55% of NHS Trusts told NOFAS-UK that they provide FASD training in some form.
- The vast majority of CCGs are not holding any form of public consultation on these issues.
- Only 23 CCGs (13.86% of responses processed) have an FASD lead.
- Only 31 Trusts (18.5%) told NOFAS-UK that they provide post-diagnostic care for those with FASD.

While the questions asked then and now don't all allow for a direct comparison, it is evident that the NICE Quality Standard has brought FASD prevention, diagnosis and support more to the fore, and that is welcomed.

2019 CCGs providing diagnosis			2024 ICBs commissioning services for diagnosis and management of people with FASD (% of those that replied)		
Children	Young people	Adults	Children (green/ amber)	Young people (green/ amber)	Adults (green/ amber)
22%	Not asked	8%	30%	28%	14%

It is evident from the responses that follow that there has been some progress across the board since 2019. However, there is still a considerable way to go before the promise of improvements called for in NICE QS 204 will have been reached. What progress there has been is patchy and for the most part without the needed profile.

[48] A Crisis of Commissioning: CCGs are Failing Government Policy on FASD, (NOFAS-UK), 2019. https://nationalfasd.org.uk/documents/A%20Crisis%20of%20Commissioning%20report%20FINAL.pdf

THE TIME IS NOW

At the time of the release of NICE Quality Standard 204, National FASD released a 141-page report, *The Time is Now: The National Perspective on Ramping Up FASD Prevention, Diagnosis and Support Services.*[49] This report should be read as a companion to our current report.

Nine remote meetings convened by the National FASD Experts Committee took place between December 2021 and March 2022. The 61 participants included paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from the Third Sector. The report highlights UK best practice and digs into specifics about improvements in services.

Topics included:

- Why it's time to think about ramping up FASD services
- Who to involve in the planning and how to get started
- What about the business case/ financing?
- Understanding elements of the diagnostic process
- Possible pathways
- Prevention
- Care management plans pre- and post-18
- How to train up locally and nationally

Key themes:

1. **There has been unprecedented work done by all major public health bodies in recent years. This work is ground-breaking. To be transformative it is now the time for joined up thinking and a clear political message to operationalise the recommendations** from the Department of Health and Social Care (DHSC), Scottish Intercollegiate Guidelines Network (SIGN), Public Health England (PHE) (now Office for Health Improvement and Disparities - OHID), the Chief Medical Officers (CMOs), the Local Government Ombudsman and the National Institute for Health and Care Excellence (NICE).
2. **FASD is preventable and increased attention is needed to ensure the CMOs' guidance on alcohol in pregnancy is understood across healthcare professions, in education and in the general public.** There is a need for both universal and targeted campaigns, as well as education in schools. The rates of unplanned pregnancies are high and good contraceptive advice is needed with women of childbearing age, alongside identification and brief advice around alcohol. Clear national communication about FASD has been lacking. The Drymester campaign and work in Greater Manchester is an example of how this can be done effectively. All midwives and all health professionals engaging with women of childbearing age must be trained on how to have these conversations without stigma. All areas should implement the NICE Quality Standard recommendations about discussing alcohol use in pregnancy and recording that information.
3. **For the first time the UK has a solid active-case ascertainment prevalence study conducted by the University of Salford. This is a wakeup call.** Roughly 3% of the population has FASD and in every school in every year group there may be 1-2 who have undiagnosed FASD. There is a need to build on this initial small study and confirm the findings in a national active-case ascertainment prevalence study. Particular attention should be given to at-risk groups where prevalence is likely to be higher (for example looked after, care experienced and adopted children, those known to mental health services and those involved in the criminal justice system).
4. **The SIGN 156 FASD diagnostic guideline for children and young people exposed prenatally to alcohol has been accepted by NICE. Training and awareness across Government and Public Health bodies is required.** The guidance is now the diagnostic guideline across Scotland, England and Wales (leaders in Northern Ireland need to clarify if this is also the case there.) Many, if not most, practitioners, commissioners and other policymakers are

[49] *The Time is Now* (National FASD), 2022. https://nationalfasd.org.uk/learn-more/policy/innovation-best-practice/

unfamiliar with SIGN 156 and the recommendations within. The Royal Colleges have a role to play. The Royal College of Paediatrics and Child Health (RCPCH) is taking a lead and can serve as an example for other Colleges. Other health professional bodies and training organisations also have key responsibilities for training. To enable a workforce with FASD understanding and awareness, it also must be incorporated into medical school undergraduate curriculum and all health and social care undergraduate courses.

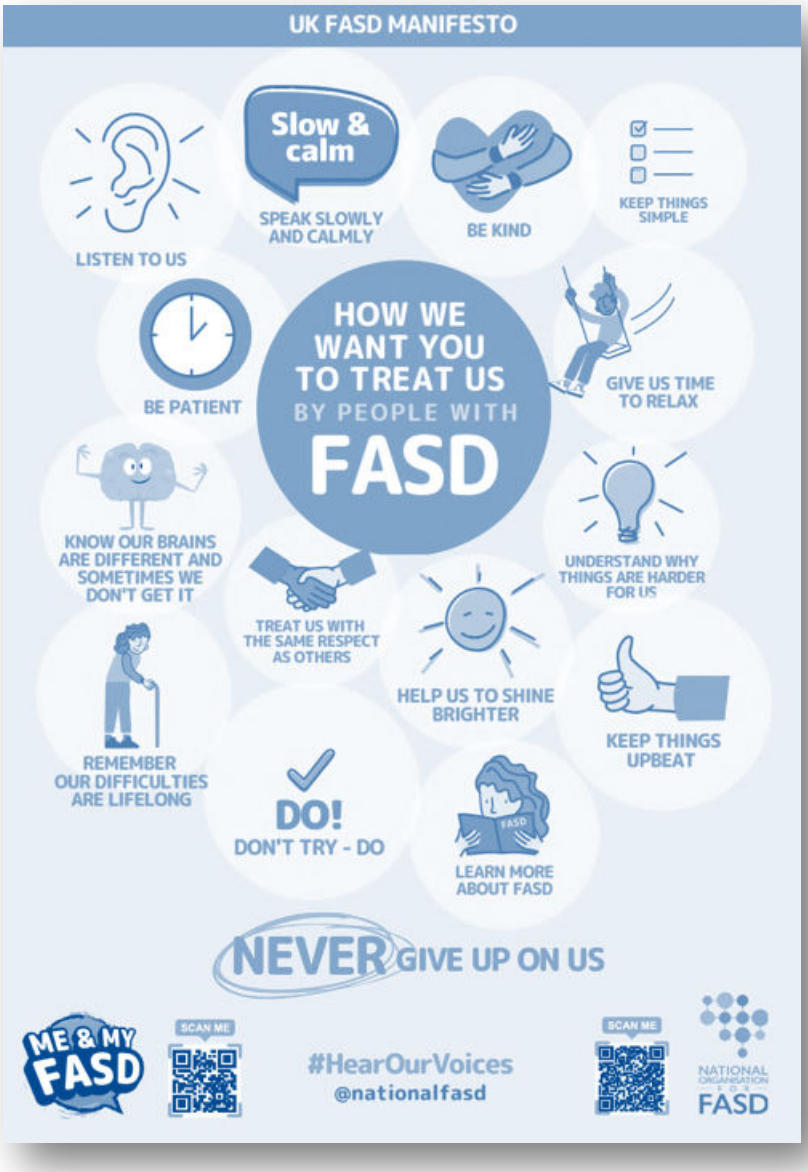
5. **Integrated Care Systems (ICSs) and NHS trusts now have the foundation they need to start to build a case for developing local pathways for prevention, diagnosis and support.** In Scotland, Health Boards also have national guidelines for the neurodevelopmental pathway including FASD that need to be implemented. The time is now, and policy makers across the UK need to act. In England the new ICSs (which bridge health and social care) can start afresh to explore creative ways to meet this underserved population.
6. **People with lived experience need to be at the core of planning and those with FASD expertise should be engaged at all levels.** The new organisations and entities that receive commissioning to enter this field must use best practice and ensure they are guided by existing FASD experts by experience.
7. **Urgent attention needs to be given as to how to set up FASD diagnosis pathways (possibly using a Hub and Spoke model) so that individual practitioners can access the multidisciplinary resources and can have appropriate peer support as required for FASD diagnosis.** Special attention should be given to the training and availability of, as a minimum, clinical psychologists and, where possible, a speech and language therapist and occupational therapist alongside an FASD trained specialist. Creative thinking is needed for how services can be shared across geographies.
8. **Care management plans are included in the NICE Quality Standard - these require special attention by policymakers. Cross-sectoral thinking and planning is needed.** Transitioning to adulthood is a key point as is ensuring that education, social services, housing, criminal justice and all sectors understand that an FASD diagnosis is lifelong and that quality of life depends on the timely provision of the support that people with FASD deserve. Repeat assessments and a mental capacity assessment, where needed, will help to ensure the vital types of support that people with FASD are entitled to is available. A special focus is needed to help individuals with FASD understand their diagnosis in ways they can access.
9. **Policy progress is extremely welcome, but action is also needed for those areas not covered.** The very young who were identified at birth as at risk of FASD need special follow up. There also needs to be guidance for adult diagnosis and support. All public health bodies have recognised FASD as lifelong and FASD does not go away when the person turns 18. Adult needs also need to be supported. Society needs to step up across sectors with support from preconception through the entire life cycle.
10. **Public policymakers must use joined up thinking to meet the identified needs of this vulnerable population and give this issue profile.** Parliament should take the lead on a Green Paper on FASD to explore how Government can maximise the impact of the recent recommendations. FASD-specific funding needs to be made available for research, training, diagnosis and support. Other countries have national funding in the tens of millions because they recognise this is an invest-to-save model. Funding needs to be available at national, regional and local levels. Private charitable foundations and trusts also will need to engage.

THE UK FASD MANIFESTO IS A BASELINE FOR INCLUDING VOICES OF THOSE WITH FASD

The UK FASD Manifesto is a request from people with FASD about how they would like to be treated
The UK FASD Manifesto[50] was created with input from more than 70 people with FASD, where they laid out how they'd like to be treated. It is a document that can help guide service development across the UK.

On its release, one young woman with FASD said, "As an adult with FASD, I wish people would understand me and treat me with the same respect as they do for people with other conditions."

Another said, "People with FASD have a right to support from medics and teachers who take the time to understand us and our disability."



[50] https://nationalfasd.org.uk/the-uk-fasd-manifesto/

THE UK FASD MANIFESTO IS CONSISTENT WITH NHS VALUES

According to the NHS Constitution for England[51], "The NHS values provide common ground for co-operation to achieve shared aspirations, at all levels of the NHS." We believe that people with FASD have a right to the improvement in services described throughout this report and if the NHS values are being met.

"Working together for patients: Patients come first in everything we do. We fully involve patients, staff, families, carers, communities, and professionals inside and outside the NHS. We put the needs of patients and communities before organisational boundaries. We speak up when things go wrong.

"Respect and dignity: We value every person – whether patient, their families or carers, or staff – as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We take what others have to say seriously. We are honest and open about our point of view and what we can and cannot do.

"Commitment to quality of care: We earn the trust placed in us by insisting on quality and striving to get the basics of quality of care – safety, effectiveness and patient experience – right every time. We encourage and welcome feedback from patients, families, carers, staff and the public. We use this to improve the care we provide and build on our successes.

"Compassion: We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. We do not wait to be asked, because we care.

"Improving lives: We strive to improve health and wellbeing and people's experiences of the NHS. We cherish excellence and professionalism wherever we find it – in the everyday things that make people's lives better as much as in clinical practice, service improvements and innovation. We recognise that all have a part to play in making ourselves, patients and our communities healthier.

"Everyone counts: We maximise our resources for the benefit of the whole community, and make sure nobody is excluded, discriminated against or left behind. We accept that some people need more help, that difficult decisions have to be taken – and that when we waste resources we waste opportunities for others."

Responses received that delay or do not prioritise implementation of Statements 3, 4 and 5 are failing to consider the NHS values as stated above.

[51] NHS Constitution, https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england#nhs-values.

WAYS FORWARD

TRACKING IMPROVEMENTS OVER TIME USING NICE QUALITY STANDARD 204 INDICATORS

Nearly all responses failed to demonstrate use of the indicators in NICE QS 204 to track improvements *over time*. This is one of the key points of Quality Standards.

NICE QS 204 includes indictors for each of the 5 statements. The committee went to great lengths to include measurable ways to track improvement over time.

For example, Statement 1 includes the following as one of the indicators:

> **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.

And as another example, Statement 3 includes:

> **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.

Please see NICE QS 204 for the rest of the indicators. These are meant to help ensure policy makers are able to track improvement over time using locally available information. This is an ideal time to begin to set in place means for tracking local data.

ADDRESSING THE UK DATA BLIND SPOT

Meanwhile, changes are underway nationally. A group of researchers led by Dr Cheryl McQuire[52] has noted that while recent landmark UK policy and guidance has called for urgent action to increase prevention, identification, and support for those affected by prenatal alcohol exposure and fetal alcohol spectrum disorder (FASD) there is a "paucity of national data undermines the feasibility of achieving this." They have proposed to address this critical FASD 'data gap'

[52] Dr Cheryl McQuire on behalf of the UK National FASD Database study team: Dr Cheryl McQuire, Amy Dillon, University of Bristol; Prof Raja Mukherjee, Surrey and Borders Partnership NHS Foundation Trust; Prof Penny Cook, University of Salford; Sandra Butcher, National Organisation for FASD; Andy Boyd, Director, UK Longitudinal Linkage Collaboration; Beverley Samways, University of Bristol; Dr Sarah Harding, University of Bristol.

by establishing the first UK National Linked Database for prenatal alcohol exposure and FASD.

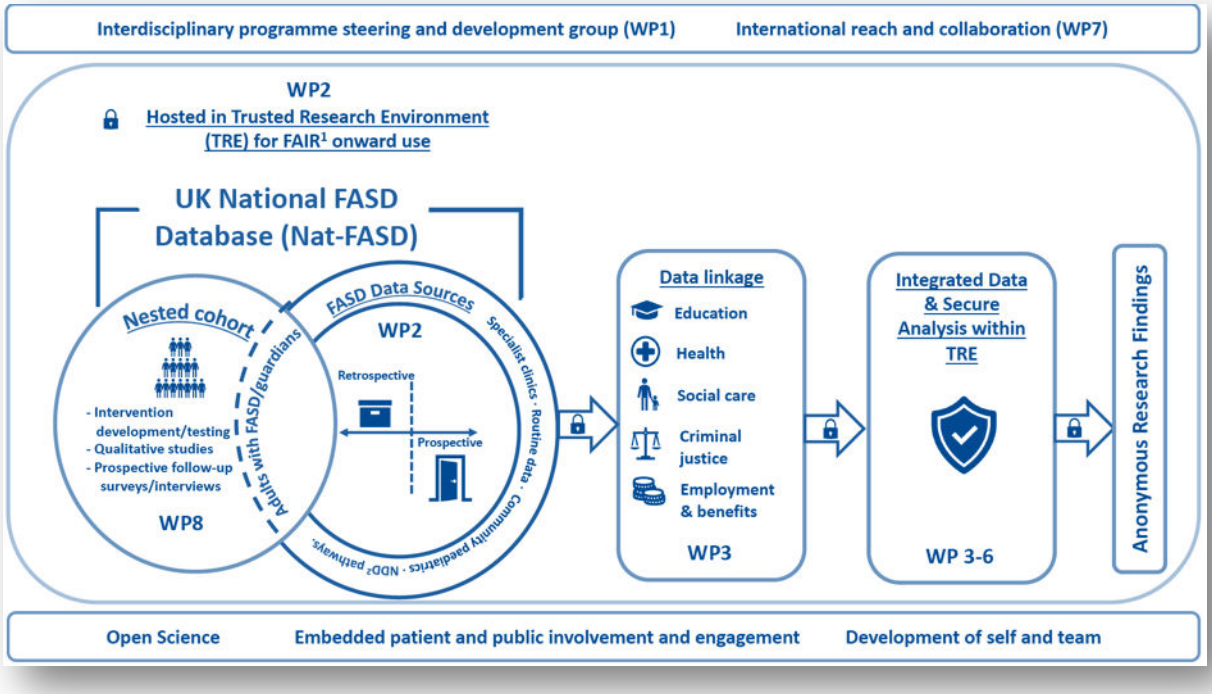
Key points include:

- "This essential, world-leading resource would securely bring together de-identified FASD assessment records from NHS and private health settings that have not previously been available for research.
- "Clinical records will be linked to health, social care, economic and criminal justice data - harnessing the rich data infrastructure available in the UK.
- "Our extensive consultations with public and professional stakeholders (including those living with FASD) have demonstrated strong support for the creation of a UK national FASD database, confirmed the feasibility of establishing this resource, and has identified Trusted Research Environments to securely house this data.
- "A UK national FASD database would transform our understanding of this prevalent, yet poorly understood condition – offering crucial insights into clinical profiles, opportunity for prevention, and interventions to improve outcomes, amounting to significant societal cost savings and vast improvements in outcomes for those living with FASD.[53]

The group is "seeking follow-on funding to make this critical resource a reality and would welcome contributions from the UK Government towards this – given the level of unmet need in our population, and the strong alignment of our objectives with contemporary data transformation and FASD policies."

A visual summary of the UK National Database for FASD (Nat-FASD) is included.

Figure: Visual summary of the planned UK National FASD Database (Nat-FASD); Blue boxes represent work packages (WPs), orange boxes represent overarching principles [1] FAIR principles for scientific data management and stewardship[6]; [b] NDD=neurodevelopmental disorder.



[53] This summary also appears in S. Butcher, supplementary evidence to Health and Social Care Committee, 6 February 2024. https://committees.parliament.uk/writtenevidence/128459/html/

NEW SNOMED CLINICAL CODING FOR FASD WILL HELP ADDRESS THE FASD 'DATA GAP'

ICBs, Health Boards and Trusts also have an exciting opportunity to help with data gathering by implementing new codes to help track those with FASD and at risk for FASD.

Dr Cheryl McQuire says, "New SNOMED Clinical Terms (SNOMED CT) codes for FASD were introduced by NHS England in April 2024. This makes it possible, for the first time, for clinicians to record a diagnosis of FASD within patients' electronic records using terms that represent the full spectrum of FASD.

"Reliable recording of FASD in electronic patient records is crucial for monitoring progress against NICE Quality Standards and for enabling further linkage to other routine data sources (e.g. through creation of a National Linked Database for FASD[54]) to better understand the needs of those living with FASD and its impact at an individual and population level."

National FASD joins with others and strongly encourage the uptake of these SNOMED CT codes in clinical practice:

> **894471000000108: Fetal Alcohol Spectrum Disorder with sentinel facial features (disorder)**
>
> **1894461000000101: Fetal Alcohol Spectrum Disorder without sentinel facial features (disorder)**
>
> **2078801000000102 - At increased risk of FASD (fetal alcohol spectrum disorder)**

As Dr McQuire states, "This will support measurement of key NICE QS outcomes including:

- Diagnosis rates for FASD (QS2 and QS4)
- Average time to diagnosis of FASD (following prenatal alcohol exposure; QS3)
- Proportion of children and young people diagnosed with FASD who have a management plan (QS5)
- Health-related quality of life for people diagnosed with FASD (QS5)."[55]

[54] Harding et al., "Addressing the fetal alcohol spectrum disorder (FASD) 'data gap': Multi-method and multi-disciplinary public engagement to ascertain the acceptability and feasibility of establishing the first UK National linked database for FASD", IJDPS (2023). https://ijpds.org/article/view/2302

[55] More information on clinical codes is available here: https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct . With thanks to Dr Cheryl McQuire, University of Bristol for this SNOMED information.

NEXT STEPS FOR STATEMENTS 1 AND 2 – COMPLIANCE IS NOT MET UNLESS SYSTEM-WIDE TRAINING IS IN PLACE AND TRACKED OVER TIME

On face value it may appear from the responses received as though the first two statements on NICE QS204 (2022) are being met by most areas. However, merely having a guideline in place may lead to patchy provision for pregnant women and does not necessarily satisfy NICE QS 204, particularly if they are not tracking improvements over time based on the indicators provided.

Statement 1 states:

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

“Maternity services should 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-judgmental 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.”

Between 276,524 - 532,814 pregnancies may be alcohol-exposed in the UK each year

The feedback in almost all responses does not give information about whether it is only maternity services that are doing this or other healthcare professionals within the trust that come into contact with pregnant women, which could be missed opportunities for prevention. Whilst some areas state that they have guidelines in place to meet statement 1 of NICE QS204, they have not all evidenced what specific information is given and whether this is both written and verbal. It isn’t clear whether all healthcare professionals have had specialist training on the risks associated with an alcohol exposed pregnancy and FASD awareness and alcohol brief interventions. Many healthcare professionals acknowledge that they have not had sufficient information on the guidelines, the harm caused by PAE or about FASD which has led to a lack of confidence in how to talk to pregnant women about alcohol and how to answer the questions and concerns that women may have (Smith et al., 2021; Schölin et al., 2021). “The messages around drinking alcohol in pregnancy have often been confusing, leaving maternity staff unclear about what is best advice and Midwives have reported anxiety about discussing alcohol and a lack of knowledge about alcohol screening and guidance” PHE (2020). Where staff have not had the training there may be significant differences in the information given by healthcare professionals which could put some pregnancies at risk.

Statement 2 states:

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

"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 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."

Not all maternity notes may have the option needed to include the information to record as per the quality standard such as a section to allow the midwife to record that they have given advice about the risks to the fetus of drinking alcohol and that they are able to document what format it has been given. NICE QS204 also states that midwives should 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.

It would be helpful to record pre-pregnancy alcohol use within the 'social context-person' section. This should also include the date stopped and if this pregnancy is a late booking, space to identify that there been consideration around the fact the pregnancy could have been alcohol exposed before pregnancy confirmation.

The Chief Medical Officers' state that there is no known safe level of alcohol use in pregnancy so any alcohol use is considered a risk to the fetus and therefore needs to be noted. SIGN 156 (2019) states that for an FASD diagnosis the requirement is confirmed prenatal alcohol exposure. Prenatal alcohol exposure information should be routinely recorded by the midwife in antenatal notes and communicated to the GP and health visitor in transfer or care documentation. This will ensure that PAE information (confirmed/confirmed absent/unknown) will be more easily accessed and will remain within the child's health records (SIGN 156, 2019). The Scottish guideline has been accepted by NICE for use in England and Wales. It would be helpful if the recording of this information was mandatory as per policy and guidance from NICE, SIGN and DHSC.

Some responses say alcohol asked about and recorded. However, it is unclear what is being recorded. Where digital health records do not require questions about alcohol to be mandatory, they could be missed. It is not clear that all women are being asked throughout pregnancy. Some areas have highlighted that they use a modified version of AUDIT-C. This is good because AUDIT-C was not designed for use with pregnant women and therefore would not identify all alcohol exposed pregnancies.

Not all areas have identified if they have a service for women who continue to drink alcohol in pregnancy, but are not alcohol

dependent and for those who are alcohol dependent.

There are around 674,448 babies born in the UK each year. If 41% (Popova et al., 2017) of those pregnancies are alcohol-exposed that would mean 276,524 pregnancies would be at risk of the effects of prenatal alcohol exposure. If 79% (Nykjaer et al., 2014, McQuire et al., 2019) were alcohol exposed then 532,814 pregnancies would be alcohol-exposed. Significant work needs to be done in raising awareness of the risks including FASD amongst both the general public and healthcare professionals.

An example of how a lack of training can prevent access to appropriate support was given by one specialist midwife who said, a pregnant lady was referred in her third trimester to a specialist midwife as she was drinking high levels of alcohol in her pregnancy. The reason she wasn't referred until her third trimester was because she was a Muslim and nobody had given her information about the risk of an alcohol exposed pregnancy nor asked her if she was drinking alcohol. This demonstrates what can happen when there is a lack of clear guidance as well as a lack of training about the risks of an alcohol exposed pregnancy.

NEXT STEPS FOR STATEMENTS 3 AND 4 – DIAGNOSIS IS NOT OUTSIDE THE REALM OF POSSIBILITY FOR MOST LOCAL AREAS

Many responses indicate that local diagnosis is not available. The first steps toward increasing local capacity is recognising these strength of what resources are available locally.

The *Time is Now* report[56] has best practice and practical ideas for those areas thinking about this issue. It was created with input from more that 60 practitioners, experts, commissioners and people with lived experience. It has whole sections on how to ramp up local diagnostic services, to explore the difference between multidisciplinary teams and multi-disciplinary assessment and to show the range of tests, many of which are available to local services, that can contribute to FASD diagnosis. In all areas of the country there are practitioners using tests on a daily basis that could inform an FASD assessment and therefore with co-ordination, but very little additional expenditure it could / should be possible to make meaningful assessments of FASD.

It says, "Urgent attention needs to be given as to how to set up FASD diagnosis pathways

> **We do not have the resources in Community and Neurodevelopmental Paediatrics to make a management plan for a child's needs, unless these are related to a specific health condition such as epilepsy. We do not produce a management plan as often the child or young person's needs are related to their behaviour or education. We cannot specify how these needs should be met as we do not have expertise in mental health, behaviour or learning support. If there are no health needs identified, then we would discharge the child or young person once a diagnosis of FASD has been made or excluded**
>
> -Response from a Trust that has 7,000 staff serving a population of 650,000 people. Using the low end FASD prevalence rate of 2%, some 13,000 people in their services are likely to have FASD

[56] The Time is Now, National FASD (2022) - https://nationalfasd.org.uk/the-time-is-now-ramping-up-fasd-support-services/?utm_source=rss&utm_medium=rss&utm_campaign=the-time-is-now-ramping-up-fasd-support-services

(possibly using a Hub and Spoke model) so that individual practitioners can access the multidisciplinary resources and can have appropriate peer support as required for FASD diagnosis. Special attention should be given to the training and availability of, as a minimum, clinical psychologists and, where possible, a speech and language therapist and occupational therapist alongside an FASD trained specialist. Creative thinking is needed for how services can be shared across geographies." (Please see earlier section on the Hub and Spoke model.)

It further states, "While at first glance some think the changes required for a full FASD assessment model are too great, there are hidden costs that this can help prevent. As one person said, 'It is difficult to know whether to go for gold or bronze, but actually many of the children are being over tested and re-referred because we aren't doing things in a good way in the first place.' This leads to money 'wasted' in the system because of this."

Example of tests used in FASD diagnosis neurodevelopmental assessment

Neuroanatomy/ neurophysiology
- ❑ Paediatric assessments
- ❑ Head circumference
- ❑ MRI (if clinically indicated)
- ❑ EEG (if clinically indicated)

Academic Achievement
- ❑ School reports
- ❑ WIAT (Wechsler Individual Achievement Test)

Sensory and motor
- ❑ Bruininks Oseretsky Test of Motor Proficiency (gross and fine motor)
- ❑ Movement ABC
- ❑ Beery Visual Motor Integration and Sensory Profile Measure
- ❑ Short Sensory Profile
- ❑ Sensory Processing Measure
- ❑ Adult and Child Sensory Profiles (W. Dunn)

Executive function, including impulse control, hyperactivity
- ❑ BADS (Behaviour Assessment of Dysexecutive Syndrome, Children)
- ❑ D-KEFS (Delis-Kaplan Executive Function System)
- ❑ BRIEF (Behaviour Rating Inventory of Executive Functioning)
- ❑ NEPSY-II

Memory
- ❑ Children's Memory Scale
- ❑ Rivermead Behavioural Memory Scale
- ❑ NEPSY-II
- ❑ Rey Complex Figure Test and Recognition Trial

Language
- ❑ CELF (Clinical Evaluation of Language Fundamentals – core, receptive, expressive)
- ❑ Communication Checklist for Children
- ❑ Communication Checklist for Adults

Cognition
- ❑ WISC (Weschler Intelligence Scale for Children)
- ❑ WAIS (Weschler Adult Intelligence Scale
- ❑ WPPSI (Weschler Preschool and Primary Scale of Intelligence)

Attention
- ❑ TEA-CH2 (Test of Everyday Attention Children)
- ❑ Delis-Kaplan Trail Making or Colour-Word Reference
- ❑ Conners Inattention Scale (Children and Adults)
- ❑ SDQ (Inattention Scale)
- ❑ Formal co-morbid ADHD diagnosis (indirect assessment)

Affect regulation
- ❑ Self Report Questionnaires (such as Child Depression Inventory)
- ❑ SDQ (Overall Score)
- ❑ Child Behaviour Checklist

Adaptive behaviour, social skills or social communication
- ❑ ABAS (Adaptive Behaviour Assessment System)
- ❑ The Social Language Development Test (Elementary and Adolescent)
- ❑ Vineland Adaptive Behaviour Scales-II
- ❑ Children's Communication Checklist
- ❑ SCQ (Social Communication Questionnaire)
- ❑ Formal co-morbid ASD diagnosis (indirect assessment)

Helpful for very young children
(multi-domain - motor, language, social skills and to some extent cognition)
- ❑ Griffiths Developmental Scales
- ❑ Bayleys Scales of Infant and Toddler Development

This is not an exclusive list.
These are examples of the range of tests that are available.
Indirect assessment is also key.
Most local areas already have access to the types of tests needed to conduct an FASD assessment.

Drawn from presentations by the Fetal Alcohol Advisory Team (Scotland), National Clinic for FASD (Surrey) and RCPCH.

Source: The Time is Now

TRAINING IS NEEDED – AND AVAILABLE

NICE QS 204 has led to increased interest among professional bodies. Below are some places that are offering training:

- **The Royal College of Paediatrics and Child Health** runs regular courses for paediatricians to help them better understand SIGN 156 diagnostic guidelines (these are accepted by NICE and in effect across England, Wales and Scotland). Designed to help consultant paediatricians, experienced doctors in community paediatrics and neuro-developmental paediatricians develop an understanding of how to assess and diagnose Fetal Alcohol Spectrum Disorder (FASD) within a local child development service including assessment of key domains, and diagnostic formulation https://learning.rcpch.ac.uk/live-courses/how-to-manage-fasd-in-community-paediatric-services/
- **Fetal Alcohol Advisory Support & Training Team** have partnered with the University of Edinburgh to develop training and professional education courses to support the prevention of alcohol exposed pregnancies and increase the capacity of the NHS workforce to provide assessments and support for individuals with FASD. They offer Europe's first PgCert in FASD, 3 x 10-week courses delivered online students will complete: 'Understanding Fetal Alcohol Spectrum Disorder (FASD): Context, Contributors & Clinical Presentation', 'Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder (FASD); 'Advanced Practice in FASD'. It is possible to take modules on a stand-alone basis as CPD. When taking the module for CPD, you can choose to take it with or without academic credit. https://www.faast.ed.ac.uk/our-services/training/
- **The National Organisation for FASD** – National FASD has an eschool with CPD accredited courses including: a free course on alcohol and pregnancy for maternity teams, an introduction to FASD course and a shorter ecourse for sexual health clinics and pharmacies. We also offer bespoke training for a range of professionals (for example our masterclass in FASD for speech and language therapists helped nearly 100 SLT across GM understand their role in FASD diagnosis, with another session planned). In addition, we offer training with our partner Seashell including a 1-day "Supporting Children and Young People with FASD" and a unique 3-day "Me and My FASD" training to help children and young people understand the diagnosis using cutting-edge resources that professionals take home with them. https://nationalfasd.org.uk/learn-more/training/
- **FASD UK Alliance Groups** – The FASD UK Alliance is an informal coalition of independent groups across the UK and many offer training. https://fasd-uk.net
- **The Royal College of Psychiatrists** have a report in development about FASD.

NEXT STEPS NEED TO ADDRESS NATIONAL INACTION ON STATEMENT 5 – THE MANAGEMENT PLAN

NICE QS 204 calls for a management plan in Statement 5. This is an area where there is very little being done across the nation, despite SIGN, DHSC and NICE recognising the importance of ensuring people with FASD receive appropriate support across their life span. SIGN 156 includes a basic example of a management plan.

The FASD UK Alliance – an information coalition of groups across the UK has had a project on a more comprehensive, less medicalised holistic FASD management plan. National FASD is proud to be a sister organisation in the Alliance. In 2023, the Alliance held a series of roundtable discussions with practitioners, policy makers, and people with lived experience to identify best practice for management plans. The goal is to create a sample management plan that provides a template for holistic and informed support for people with FASD. In the future more will be available at: https://fasd-uk.net/2023/05/25/project-on-fasd-management-plans/.

REACH OUT – HELP IS AVAILABLE WHEN TAKING THE NEXT STEP ON SYSTEM-WIDE ACTION IN YOUR AREA

As mentioned at the outset of this report, our intention with this project is to get a national picture of steps being taken to improve quality of care based on NICE QS 204.

We are aware that there are competing pressures for time, attention and resources within local systems and on the national scene. However, implementation of NICE QS 204 will in the end help relieve pressures when people have the correct diagnosis and support.

The ratings system used here is, as we have noted, imperfect. But it's at least an attempt to set a baseline upon which progress can be built. It's not intended to call out any specific area.

We stand ready to collaborate in building local expertise in any area looking to continue progress in this area. Please email us at info@nationalfasd.org.uk for more details.

National FASD has a proven track record of working with ICBs, Trusts and other organisations to connect forward-thinking commissioners and local practitioners and service providers with national experts and resources. We have experience in arranging:

- An initial consultation to assess your needs
- Roundtables
- Training days for key leads
- System-wide training and networking
- Expert-reviewed and internationally acclaimed resources created in collaboration with people with FASD and their families

Our goal is to create brighter futures and to decrease incidence of FASD.

In addition, the independent FASD UK Alliance organisations each have their own offers. Please see: https://fasd-uk.net for a catalogue of organisations.

APPENDICES

Appendices Table of Contents

INTEGRATED CARE BOARDS

QUESTIONS POSED TO ICBS

NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder was published 16 March 2022 (https://www.nice.org.uk/guidance/qs204)

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

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.

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.*

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.)

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

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.)

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.)

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.)

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?

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 note – requests to 5 London ICBs were sent separately and they did not receive question 4.*

ICBs were then sent a second question:

1. Has your ICB commissioned services for diagnosis and management of people with FASD (Fetal Alcohol Spectrum Disorder)
a) For children
b) For young people
c) For adults

2. If yes, please say who has been commissioned to do this and what the pathway is, and provide any relevant documents.

ICBS DETAILED RESPONSES

NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - All providers monitor NICE Quality Standards. ICB can confirm that this has been circulated to maternity and neonatal providers.
Q2 - All provider organisations are required to review and monitor NICE Quality Standards.
Q3 - ICB can confirm that this has been circulated to provider maternity and neonatal teams.
Q4 - No
Q5 – Statements 1-5 - Provider led
Q6 - Not applicable
Q7 - Provider organisations review against NICE Quality Standards.
Q8 - Patient experience is measured via a variety of service user engagement strategies, including maternity and neonatal voices partnership and ICB Patient Engagement Forum. Complaints, concerns and compliments are also monitored via Patient Advice and Complaints Service, of which there have been no themes or trends in relation to NICE Quality Standard 204.
Q9 - No.
Comment from National FASD – This ICB has not demonstrated it is taking action specific to NICE Quality Standard 204 and has not indicated it understands the QS is relevant to a wider range of professionals than just maternity and neonatal teams. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - No. Although not specifically commissioned, current service provision for the identified groups would include FASD within differential diagnoses and identify management plans as part of speciality commissioning.
C2 – Not applicable
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD, though it has stated FASD diagnosis is included in current service provision. Families should use this statement if they encounter challenges with accessing FASD diagnosis and support.

NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - NICE standards are provided nationally to all stakeholders/users. There is no requirement to circulate locally.
Q2 - No. Meeting NICE standards is a co-requirement of the NHS Standard Contract and applies to all providers in line with the responsibilities identified by NICE.
Q3 - As per Q2 above.
Q4 - No this would happen at provider level in line with the NHS Standard Contract and in line with the responsibilities laid down by NICE.
Q5 - N/A but for queries on all statements below please contact CYPM (NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES ICB - M1J4Y)
Q6 – None
Q7 - Reported through contract review meetings.
Q8 - N/A but individual providers may be able to advise.

Q9 – None
Comment from National FASD – This ICB has not demonstrated it is taking action specific to NICE Quality Standard 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 – a) no; b) no; c) no
C2 – no response
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS BIRMINGHAM AND SOLIHULL ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - NHS Birmingham and Solihull do hold the information requested. This quality standard has been shared with some teams/services including: ICB Children in Care, ICB Safeguarding, Community Paediatrics Service, ICB Children's Commissioning.
Q2 - NHS Birmingham and Solihull do hold the information requested Unaware of a direct request
Q3 - NHS Birmingham and Solihull do hold the information requested. ICB Safeguarding, ICB Children in Care, Community Paediatrics Services (University Hospital Birmingham (UHB) and Birmingham Community Healthcare (BCHC) Trust), ICB Children's Commissioning.
Q4 - NHS Birmingham and Solihull do hold the information requested. Unaware of direct consideration but the development of the ICB board level directed 2024/25 commissioning plan will include consideration of FASD requirements, particularly in relation Community Paediatrics Service provision across the ICS.
Q5 - NHS Birmingham and Solihull do not hold the information requested Please contact the service providers directly. University Hospitals Birmingham NHS Foundation Trust foi.uhb@uhb.nhs.uk; Birmingham Community Healthcare NHS Foundation Trust Foi.bchc@nhs.net; Birmingham Women's and Children's NHS Foundation Trust; Bwc.freedomofinformation@nhs.net
Q6 – See above
Q7 – See above
Q8 – See above
Q9 – See above
Comment from National FASD – This ICB indicates it is considering FASD requirements in relation to commissioning of community paediatrics service and that is a positive step. Its reply is silent on advice to pregnant women included in Statements 1 and 2. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - No formal FASD service is commissioned. For further information please contact the trusts directly: University Hospitals Birmingham NHS Foundation Trust, Birmingham Community Healthcare NHS Foundation Trust
C2 - Please contact the trusts directly
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD (though in its reply regarding the NICE QS 204 they indicate this will be considered in 2024/25). They refer to the local trusts. This shows the loop too many people with FASD and their families face. While University Hospitals Birmingham Trust did not reply by the statutory deadline, Birmingham Community Healthcare NHS Foundation Trust said, "Some diagnoses are given by the community paediatrician however this is challenging due to the lack of a defined pathway and the evidence required from multi-disciplinary team. Children with concerns about possible ADHD/ASD would be referred directly to the ADHD/ASD pathway. FASD may be considered as part of the presentation and assessment however it is not an assessment pathway for FASD specifically and a diagnosis would not be given during this assessment. If there are concerns which might suggest this [sic] children can then be referred to community paediatrics for assessment but these would only be seen if fulfilling the remit of our current referral criteria for Community Paediatrics and wouldn't necessarily be seen for FASD assessment specifically if there are no developmental concerns as part of this."

NHS BLACK COUNTRY ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - The ICB does not hold this information. A variety of guidance & standards is routinely forwarded to partners & stakeholders; however all NHS organisations are expected to take into account the recommendations in NICE clinical guidelines when deciding what treatments to offer people.
Q2 - No. The ICB is responsible for ensuring that all NICE guidelines & standards inform commissioning activity & therefore considers that this is relevant to all teams. We

cannot comment on other organisations; you may wish to redirect your request to the local Trusts as detailed below. Dudley Group NHS Foundation Trust, Russells Hall Hospital, Pensnett Road, Dudley, DY1 2HQ. Email: dgft.foi@nhs.net; Sandwell & West Birmingham NHS Trust, Corporate Governance Team, Trust Headquarters, Sandwell General Hospital, Lyndon, West Bromwich, B71 4HJ. Email: swb-tr.SWBH-GM-FOIRequests@nhs.net; Walsall Healthcare NHS Trust, Manor Hospital, Moat Road, Walsall, WS2 9PS. Email: WHT.FOI@nhs.net; The Royal Wolverhampton NHS Trust Governance and Legal Department, The New Cross Hospital, Wolverhampton, WV10 0QP. Email: rwh-tr.foi@nhs.net
Q3 - Please refer to question 2 response.
Q4 - Yes. ICB Board members are responsible for providing oversight and assurance to the delivery of a range of statutory functions, including those specifically relating to commissioning activity. This assurance & oversight function ensures that all NICE guidelines/ standards have been taken into consideration when making commissioning decisions. The NHS standard contract requires providers to give due consideration to NICE standards/ guidelines & there are robust arrangements in place to escalate any compliance issues. Our Board :: Black Country ICB
Q5 - The ICB does not allocate responsibility for specific statements. However, Sally Roberts the Chief Nurse/Deputy Chief Executive is the executive lead for CYP & maternity services; & Dr Ananta Dave the Chief Medical Officer is the executive lead for learning disability/autism services. Our Board :: Black Country ICB
Q6 - The ICB have not created a review sheet & would recommend you redirect your request to the four Trusts detailed in question 2 response.
Q7 - The NHS standard contract requires providers to give due consideration to NICE standards/ guidelines & there are robust arrangements in place to escalate any compliance issues.
Q8 - This is part of our wider partnership & patient involvement approach, which includes place-based partnerships for Walsall, Wolverhampton, Sandwell and Dudley, & an emerging Black Country wide Integrated Care Partnership.
Q9 - No. Not applicable.
Comment from National FASD: This ICB has not demonstrated in their reply that they are taking specific action on NICE Quality Standard 204.

Commissioning Response:
Comment from National FASD: This ICB did not reply by the statutory deadline.

NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning

✗	✗

NICE QS Response
Q1- It has not been circulated by BNSSG ICB.
Q2 - BNSSG ICB has not asked teams or other organisations whether the quality standard applies to their service and is not aware if they have been asked this question by another body.
Q3 - BNSSG ICB cannot confirm which teams / organisations have identified that the quality standard is applicable to them.
Q4 - The lead ICB board members have not yet included consideration of FASD and the implementation of the quality standard in their decision making about service provision and assessment of local need.
Q5 – Statements 1-5 - The maternity, paediatric, general practice and other services that the ICB commissions are responsible for delivering care to pregnant people and their families and also to children and young people, which would include the interventions included in this quality standard.
Q6- No review sheet has been created.
Q7- The current structure and ways of working in BNSSG ICB means that commissioned providers are responsible for responding to NICE quality standards.
Q8 - BNSSG ICB as an individual organisation is not responding directly to this quality standard.
Q9 – No
Comment from National FASD: This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning response:
C1 - The ICB does not hold this information, please contact the Trust directly: University Hospital Bristol and Weston NHS Foundation Trust (UHBW)
C2 - Further information can be found here: https://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/stmichaels- hospital/what-we-do/fetal-medicine-unit/
Comment from National FASD – Whilst it is curious the ICB doesn't know if it has commissioned services, the Trust response states that there are no commissioned services.

NHS BUCKINGHAMSHIRE, OXFORDSHIRE & WEST BERKSHIRE (BOB) ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Not applicable. NICE quality standards are advisory for commissioners and providers. The relevant ICB commissioning leads have responsibility to review quality standards applicable to their area of responsibility and use the quality standards to influence commissioning and quality oversight as appropriate. Providers have a responsibility to use quality standards relevant to the services that they provide to support quality improvement work and provide internal assurance as appropriate for that organisation.
Q2 - See answer to Q1
Q3 - Data not held
Q4 - No evidence of this.
Q5 - 8 - Not applicable – please see answer to Q1
Q9 - Not applicable
Comment from National FASD: This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term which encompasses a range of neurodevelopmental impairments, which can result in cognitive, physical and behavioural difficulties for individuals. There are locally commissioned services within Mental Health, Learning Disability and Neurology which are able to identify and treat the difficulties associated with FASD. Due to this, national specialist assessment and treatment programmes solely for the diagnosis and treatment of FASD in children, adolescents and adults are not normally funded.
C2 - Not applicable.
Comment from National FASD: This ICB has not commissioned services for diagnosis and management of people with FASD. It is interesting that the response does not mention the role of paediatrics. Without using the indicators from NICE QS 204 how do they know that these services are managing the increasing need to identify and support those with FASD?

NHS CAMBRIDGESHIRE & PETERBOROUGH ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Yes, it was circulated to our community provider Trusts Cambridgeshire and Peterborough NNS Foundation Trust (CPFT) and Cambridgeshire Community Services NHS Trust (CCS).
Q2 – Yes
Q3 - CPFT and CCS
Q4 - Our paediatric consultants in the community (CPFT/ CCS) have raised via contract meetings and e- mail that they have seen more cases being referred as a result of the NICE guidance.
Q5 – Statement 1 - Women are asked at booking whether they consume alcohol and their response is recorded in the maternity records. They are advised that there are no safe limits. Provider Trusts responsible: Namely, CCS, CPFT, Cambridge University Hospitals NHS Foundation Trust (CUHFT), and North West Anglia NS Foundation Trust (NWAFT); Statement 2 - Women who indicate that they are drinking and requiring specialist support are referred at this point and advised that there are no safe drinking limits during pregnancy. Women who have indicated that they are drinking will have ongoing counselling throughout their pregnancy. Provider Trusts responsible: Namely, CCS, CPFT, Cambridge University Hospitals NHS Foundation Trust (CUHFT), and North West Anglia NS Foundation Trust (NWAFT); Statement 3 - Neurodevelopmental pathways currently under review – Public services consultancy commissioned by ICB; Statement 4 - Neurodevelopmental pathways currently under review; Statement 5 - Neurodevelopmental pathways currently under review.
Q6 - Not to date. Consideration will be given to including this in our quality schedules which are presently in development.
Q7 - Scoping through community paediatrics review of neurodevelopmental pathways.
Q8 – This still has to be determined
Q9 – n/a
Comment from National FASD – This ICB is starting to take action and has ND pathways under review, but it has not identified specific FASD training. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - no
C2 – n/a
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS CHESHIRE & MERSEYSIDE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response

Q1 - NHS Cheshire & Merseyside ICB has not directly circulated the above NICE guidance.
Q2 - NHS Cheshire & Merseyside ICB has not asked other organisations whether NICE Quality Standard 204 is applicable to their service(s) and as a result does not hold any information on any organisations which have identified that this NICE guidance is applicable to them.
Q3 – See above
Q4 - NICE FASD Quality Standard 204 is not specifically considered in decision making about service provision and assessment of local need for learning disability and autism services. It is standard practice to ask commissioned providers to take account of all relevant NICE guidance in the delivery of the services commissioned.
Q5 - NHS Cheshire & Merseyside ICB does not hold information detailing a specific person(s) responsible for the above NICE Quality Standard 204 statements. Please note there is no one single referral process for FASD across the Cheshire and Merseyside area currently. However, a FASD Steering Group has been established with colleagues from across the region to inform the development of future referral pathways, which includes colleagues from maternity services, children services, and parents/carer from forums across the region. The steering group is also working alongside colleagues to map out areas/NHS Trusts where this is available and how they can influence this to be replicated wider across the region.
Q6 - NHS Cheshire & Merseyside ICB has not created or holds a review sheet in relation to NICE Quality Standard 204. As previously advised, each commissioned provider of NHS services by the ICB would be expected to respond to relevant NICE guidance when it is issued through their own internal clinical governance structures.
Q7 – See above
Q8 – See above
Q9 - NHS Cheshire & Merseyside ICB does not hold, or has created, any documents related to improvement of quality of care specifically regarding NICE Quality Standard 204.
Comment from National FASD – This ICB has set up a steering group on FASD which is encouraging but the ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:

C1, C2 - NHS Cheshire & Merseyside ICB has not directly commissioned any dedicated services specifically for FASD. However, the Beyond Programme (Cheshire and Merseyside ICS' Children's Transformation Programme) delivered via Alder Hey Children's Hospital NHS Foundation Trust, is currently working on undertaking a scoping exercise of services across Cheshire & Merseyside which incorporates diagnosis and management of FASD. There is also a steering group set up which intends to ensure there are clearly defined referral/surveillance pathways for FASD for NHS Cheshire & Merseyside ICB patients.
Additionally, a maternity element will also link in with this work to ensure the 2022 NICE quality standard QS204 is implemented and being followed by maternity services, with clearly defined referral pathways and recording of alcohol affected pregnancies. Furthermore, it is the intention to upskill staff and have a shared recommended training toolkit for Midwives within all NHS Trusts, which was produced by the National organisation for FASD in 2023.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. It has stated it is working on this, and that is welcome. The further information provided in this commissioning answer about work being done is very encouraging.

NHS CORNWALL AND ISLES OF SCILLY ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response

Q1- Cornwall and Isles of Scilly Integrated Care Board (ICB) commissioning leads, paediatricians in (Royal Cornwall Hospitals Trust) RCHT and clinical staff in (Cornwall Partnership Foundation) CFT are fully aware of NICE standard and the service development improvement plan and specification for neurodevelopmental pathway and neurodevelopmental service articulates the need to work across CFT and RCHT to ensure the right skill mix and process to address foetal alcohol spectrum disorder (FASD) as one of the diagnosis that may need to be explored under this pathway. The Neurodiversity Strategy, approved by Quality and Pathways of Care Committee in the ICB and the Council Cabinet, clearly identifies FASD as one of the potential diagnoses in these clinical pathways of care. However, a clear response to the requirement and skill mix is still in development, we have recognised a skill mix within the service to currently adhere to the NICE guidance. We are therefore exploring a commissioning policy in the interim so that when clinical teams have

identified through their assessment in the ND pathways that FASD diagnosis needs to be explored, we can refer cases to specialist teams nationally.
Q2 - Please see Q1.
Q3 - Please see Q1.
Q4 - We do not receive specific reporting against NICE standard compliance – this is held with providers, however but the strategy and approach has been agreed, see above.
Q5 – Statement 1 - RCHT Maternity and Neonatal services have responsibility for statement 1: advice on avoiding alcohol in pregnancy. RCHT Guidelines are in place which include accessing and providing advice. It is outlined in the RCHT Antenatal Booking, Antenatal Care, and Information Clinical Guideline V3.1; Statement 2 - Fetal alcohol exposure in asked about and recorded, RCHT Guidelines are in place. It is outlined in the RCHT Antenatal Booking, Antenatal Care, and Information Clinical Guideline V3.1 and 'Alcohol and Substance Use in Pregnancy, Labour and Post Delivery Clinical Guideline' RCHT, November 2022; Statement 3 - Children and young people with probably prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for a neurodevelopmental assessment through the pathway, clinicians will then triage and determine the appropriate diagnostic route; Statement 4 - Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have neurodevelopmental assessment if there are clinical concerns as part of the neurodevelopmental pathway; Statement 5 - Children and young people with a diagnosis of FASD have a management plan to address their needs as part of the neurodevelopmental pathway.
Q6 – ICB do not have a review sheet this would be for NICE leads within our providers to create.
Q7 - We monitor our providers to be assured that they are continually improving the quality of the care they deliver, for this standard we will expect our providers to be assure us that they are acting as stated in the standard.
Q8 - Parents have been involved in the neurodevelopmental pathway strategy and implementation approach, but not specifically in relation to implementation of NICE Quality Standard 204.
Q9 - The ICB has not created any other documents related to improvement of quality of care regarding NICE Quality Standard 204.
Comment from National FASD – This ICB response demonstrates that it is taking action on NICE QS 204. It is encouraging that FASD is being included in a neurodiversity strategy and consideration is being given to the needed skills set for diagnosis. It is not clear from the resopnse if the training that is called for in NICE QS 204 has been carried out to enable the full implementation of the QS across sectors as identified by NICE QS 204. Reliance on an interim commissioning strategy that directs people toward the FASD national service in Surrey is not ideal given the distances involved and the waitlist for that service. Because of the prevalence they should have local provision for diagnosis with recourse to a national resource if they are unsure of the diagnosis.

Commissioning response:
C1: Cornwall and Isles of Scilly Integrated Care Board does not commission specific services for the management of Fetal Alcohol Spectrum Disorder for children, young people, or adults.
C2: none
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS COVENTRY AND WARWICKSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 – Yes
Q2 - Yes, The Coventry and Warwickshire Special educational needs and disabilities (SEND) Steering group were asked to review guidance and implementation.
Q3 - Local Maternity and Neonatal System (LMNS) and Children's Transformation (which includes SEND).
Q4 - The ICB generally would not be responsible for each National Institute for Health and Care Excellence (NICE) Quality standard. Providers are expected within their relevant areas to implement relevant NICE guidance. As commissioners we would support providers if made aware of any issues on the implementation and of course review service specifications to ensure relevant guidance is added.
Q5 - Please see response to Question 4.
Q6 -- The ICB does not have a NICE lead.
Q7 - Via commissioner/provider meetings and/or specific meetings such as LMNS complex pregnancy group or SEND meetings.
Q8 - LMNS has a complex pregnancy sub group, discussions regarding care, support and pathways for alcohol dependent women are part of this agenda.
Q9 – No
Comment from National FASD: This ICB has taken some steps but has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - No – whilst we have services which can provide treatment and support for symptoms (e.g. mental health, neurodevelopmental), we do not have a standalone commissioned service or pathway.
C2 – Not applicable.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS DERBY AND DERBYSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Commissioners and service providers work to the NICE Quality Standards that are relevant to the services they provide and the interventions they deliver.
Q2 - Commissioners and service providers work to the NICE Quality Standards that are relevant to the services they provide and the interventions they deliver.
Q3 - Maternity, Midwifery, Health Visitors, Primary Care, Paediatrics, and ND Clinical Assessment Teams.
Q4 - We are compliant with NICE Quality Standard 204 but we acknowledge the need for more education and training in the recognition of FASD alongside other presentations. FASD pathway has been considered locally and the system was represented at a recent conference.
Q5 – Statements 1-5 - Prof Dean Howells, Executive Chief Nurse - SRO for CYP Jo Hunter, Director of Quality - Deputy SRO for CYP
Q6 - We do not have a review sheet as NICE QS 204 is embedded within processes and procedures for Maternity, Midwifery, Health Visiting and Primary Care.
Q7 - NICE QS 204 is embedded within processes and procedures for Maternity, Midwifery, Health Visiting and Primary Care.
Q8 - Patient responses to the questions relating to NICE QS 204 are recorded within patient records.
Q9 - No.
Comment from National FASD – This ICB claims to be compliant with NICE QS 204 though it has not provided further information. It has recognised the need for more training as called for in NICE QS 204 and without that training it is unlikely to have widespread awareness and understanding of the latest guidance and guidelines throughout its system.

Commissioning Response:
C1 - a) For children - This would be picked up by the Community Paediatric Team at Derbyshire Health Community Services (DCHS) as below:
b) For young people - For young people and adults the case can be referred to specialist genetic service at Nottingham University Hospital.
c) For adults - As above.
For Derbyshire Health Community Services: Community paediatricians are doctors experienced in working with children and young people for an identified health need. Our community paediatricians are specially trained in child health and development. They see children for a wide variety of reasons. It may be to assess: Developmental concerns in under 5's; Specific developmental problems (such as Autism (ASD) or ADHD) Learning difficulties (if a medical or neurodevelopmental cause is suspected) Complex physical disabilities Sensory impairments such as visual difficulties or hearing loss; Specific genetic conditions. Referrals to the service are via Single Point of Access (SPOA) all referrals are reviewed in order to identify the most appropriate service. The Community Paediatric team may give you advice or signpost you to another more suitable service.
C2 -
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. While a SPOA can be appropriate for FASD diagnosis, the response hasn't mentioned any recognition of the need for increased training in FASD or the implementation of SIGN 156, which states that prenatal alcohol exposure should be 'actively considered'. Referral of young people and adults to a specialist genetic service is not appropriate and overwhelming to the genetic service.

NHS DEVON ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 – 2 - No. NICE state that Quality Standards are not mandatory and are based on their other guidance and NICE accredited sources, therefore they are not discussed at NHS Devon's NICE Planning Advisory Group (NPAG).
Q3 - NICE state that Quality Standards are not mandatory and are based on their other guidance and NICE accredited sources, therefore they are not discussed at NHS Devon's NICE Planning Advisory Group (NPAG). Commissioners for maternity and children services will refer to NICE publications as part of any planned service reviews.
Q4 - NHS Devon does not commission services specifically for FASD. NHS Devon publishes information about our Board members
Q5 - The ICB does not commission services specifically for FASD. Statement 1 - please refer to the response provided to answer question 4; Statement 2 - 5 - NHS Devon does not commission FASD specific services.
Q6 - NHS Devon does not hold this information.
Q7 - QS204 Fetal Alcohol Spectrum Disorder is not discussed at NPAG as Quality Standards are not mandatory.
Q8 - NHS Devon is not acting at this point in time in relation to QS204 Fetal Alcohol Spectrum Disorder.
Q9 - Not applicable.

Comment from National FASD: *This ICB clearly states it has not taken steps on NICE QS 204. It has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.*

Commissioning Response:
C1, C2 - The ICB does not commission services specifically for FASD.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS DORSET ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 – 9 - I can advise that NHS Dorset does not hold the information requested. You may be able to obtain the information you require by making your request to: University Hospitals Dorset on foi@uhd.nhs.uk; Dorset County Hospital NHS Foundation Trust on FOI@dchft.nhs.uk; Dorset Healthcare University NHS Foundation Trust on https://www.dorsethealthcare.nhs.uk/about-us/your-information/freedom-of- information.
Comment from National FASD: This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning response:
C1 – a, b, and c) No, NHS Dorset ICB have not commissioned a service for diagnosis and management of people with FASD
C2 - Please see response to Q1a.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS FRIMLEY ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1- This information is not held by the ICB. We suggest you contact the providers as they may be able to assist with this query. Child & Family Health Surrey Berkshire Healthcare Foundation Trust
Q2 – See above
Q3 – See above
Q4 – See above
Q5 – Statement 1 - LMNS leads. Information is available on the maternity website. Smart text sent to women linking to website: Alcohol | Frimley Maternity Health and Care (frimleyhealthandcare.org.uk); Statement 2 - LMNS leads. This is included in the booking process and smart text provided. Ongoing conversations particularly where safeguarding risks identified; Statement 3 - Quality Team through quality oversight of block contracts. Clinicians refer to neurodevelopmental team if required and where a child needs a specific FASD assessment an individual funding request can be made for the specialist service at SABP; Statement 4 - Quality Team through quality oversight of block contracts. Clinicians refer to neurodevelopmental team if required and where a child needs a specific FASD assessment an individual funding request can be made for the specialist service at SABP; Statement 5 - Quality Team through quality oversight of block contracts. Children referred to SABP FASD service have their plan returned to the referring clinician.
Q6 - This information is not held by the ICB. We suggest you contact the providers as they may be able to assist with this query.
Q7 - This information is not held by the ICB. We suggest you contact the providers as they may be able to assist with this query. Child & Family Health Surrey Berkshire Healthcare Foundation Trust
Q8 – See above
Q9 – See above
Comment from National FASD: This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision. Because of the prevalence of FASD, referral of all but challenging cases to a national resource is not sustainable. NICE requests provision at local level.

Commissioning Response:
C1a, C1b - Children and young people with suspected FASD are managed by community paediatricians for holistic care of their presenting symptoms. Where the paediatrician feels the child or young person would benefit from an FASD assessment we commission on a case-by-case basis from the FASD Service at Surrey and Borders Partnership. Management advice is given to the community paediatricians from this specialist service

and the children or young person's care is overseen by the paediatrician.
C1c - This is not a commissioned service for Berkshire Healthcare NHS Foundation Trust.
Please see link for information for Surrey and Borders Partnership NHS Foundation Trust.
C2 - Please see answers provided above.
Comment from National FASD: This ICB states it is not commissioning local diagnostic services for FASD diagnosis and support, but commissions the National FASD clinic on a case-by-case basis.

NHS GLOUCESTERSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Yes, this has been circulated to Gloucestershire Maternity & Paediatric Services
Q2 - Yes, within Maternity & Neonatal services
Q3 - Maternity & Neonatal services
Q4 - This NICE QS involves Maternity and Children's Health Teams across the system. A gap analysis has been undertaken and actions identified. This work is currently ongoing.
Q5 – Statement 1 - Assistant Director of Midwifery/Clinical Lead Gloucestershire Local Maternity and Neonatal System; Statement 2 - Assistant Director of Midwifery/Clinical Lead Gloucestershire Local Maternity and Neonatal System; Statement 3 - CYP Clinical Programme Group/Children's commissioning team; Statement 4 - CYP Clinical Programme Group/Children's commissioning team; Statement 5 - CYP Clinical Programme Group/Children's commissioning team
Q6 – No
Q7 - Collaborative work is underway and will be monitored by LMNS and CYP Clinical Programme groups.
Q8 - The Gloucestershire Maternity & Neonatal Voices Partnership engage with recent users and collate feedback of their experiences. This is collated into themes and included in feedback to services so that improvements can be made.
Q9 – No
Comment from National FASD – This ICB is taking action and it is encouraging that there is a gap analysis undertaken and actions identified.

Commissioning Response:
C1 - The ICB does not specifically commission services for the diagnosis and management of fetal alcohol spectrum disorder, but our health providers follow relevant NICE guidance for different conditions.
C2 – n/a
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS GREATER MANCHESTER ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Full implementation of the standard is a specific priority within the NHS Greater Manchester (GM) Joint Forward Plan which states that we will "Build on our activity to date on tackling the harms associated with alcohol consumption in pregnancy by fully implementing the NICE Quality Standards for Foetal Alcohol Spectrum Disorder (FASD)". This includes a hyperlink to the Quality Standard. The standard has been specifically presented to The Children and Young People's Wellbeing Board, The School Readiness Board, The Maternity Programme Board, The Greater Manchester Population Health Team, The Drug and Alcohol Commissioners meeting, GM Public Health Leadership Group and The Clinical Effectiveness and Governance Meeting for wider distribution. The standard is presented as part of a commissioned training programme delivered to health and social care staff, carers and families, police, adoption and foster staff, drug, and alcohol staff and primary care across GM. In the 2 years since the publication of standards 26 virtual training sessions and 2 face to face sessions have been delivered to over 2000 participants.
Q2 - Yes, significant work has taken place to ensure the standard is considered across this organisation
Q3 - The standard has been included in the Joint Forward Plan, Maternity Equity Plans and Children and Young People Plans. It has been socialised specifically within the Local maternity system, clinical effectiveness and governance committee and population health committee. Outside the NHS GM, the following key partners have been engaged. All early year's services, CAMHs, Adoption and Fostering services, Primary Care, Paediatricians, Strategic Clinical Network, Drug and Alcohol Services, Maternity Services, Police, Safeguarding Teams and VCSE organisations.
Q4 - Full implementation of the standard is a specific priority within the NHS GM Joint Forward Plan which states that we will "Build on our activity to date on tackling the harms associated with alcohol consumption in pregnancy by fully implementing the NICE Quality Standards for Foetal Alcohol Spectrum Disorder (FASD)". This includes a hyperlink to the Quality Standard. This plan covers the entirety of NHS GM. The standard has

been included in Maternity Equity Plans and Children and Young People Plans. It has been socialised specifically within the Local maternity system, clinical effectiveness and governance committee and population health committee.
Q5 - Overall leadership sits with the NHS GM Population Health Committee, but responsibility for delivery is more dispersed. Day to day operational leadership is provided by a Strategic Lead for Population Health.
Statements 1 and 2 - monitoring the implementation of the Alcohol exposed pregnancy standard operational policy (SOP); Strategic Lead – Population Health;
Statements 3 – 5 - Early years and school readiness board. Strategic Lead – Population Health
Q6 - N/A
Q7 - FASD is included as a priority in the GM ICP 5 Year Joint Forward Plan. Building upon our exemplar activity to date around tackling the harms associated with alcohol consumption in pregnancy by fully implementing the NICE Quality Standards for Fetal Alcohol Spectrum Disorder (FASD) . This response includes the following examples of activity:
Statement 1 - Co-produced standard Maternity Alcohol exposed pregnancy (AEP) operational policy that ensures alcohol use it discussed and documented on 3 occasions during pregnancy. This is overseen by the strategic clinical network; Commissioned CPD Accredited AEP and FASD training that all health and social care staff across GM have been encouraged to access. Commissioned until March 24; AEP prevention pathways included in the GMEC equality and equity action plan; AEP and FASD included in Best Start Programme Plan; Award winning Drymester media campaign – website and social media platforms. (Commissioned till March 2024).
Statement 2: Co-produced a standard Alcohol exposed pregnancy operational policy that ensures alcohol use it discussed and documented on 3 occasions during pregnancy. This is overseen by the strategic clinical network; Commissioned CPD Accredited AEP and FASD training until March 24. All health and social care staff across GM have been encouraged to access.
Statement 3: Worked with the school readiness board to ensure all staff who work in early years are offered the opportunity to access AEP and FASD training. 20 face to face sessions and 32 virtual sessions delivered since June 2020. Over 1000 professionals have accessed the training in the last 12 months; Developed a speech and language therapist (SLT) FASD podcast. Commissioned SLT training. Delivered to 95 SLTs on 30/01/2024. A further training session organised for May 24; Supported GP excellence in developing a FASD primary care podcast with leading clinical expert Professor Raja Mukherjee. Download over 17,000 times.
Statement 4: Commissioned Surrey and Boarders NHS National FASD clinic to deliver FASD diagnostic training X 2 days. Second session delivered on 30/01/2024. 21 community and hospital-based pediatricians attended; Commissioned the National FASD Clinic to provide consultation and clinical supervision to GM Clinicians until March 25; Developed a pilot FASD diagnostic pathway that has been agreed in principle but has not been taken forward; Commissioned a 18-month support package (until June 2025) from National FASD to support families across GM who care for children with FASD.
Statement 5: The strategic lead for alcohol harm attended a roundtable facilitated by National FASD to discuss what needed to be included in a management plan; Support package being offered by National FASD to empower families to ask for a management plan; National FASD developing a management plan and sessions to be delivered across GM to professional groups to support the utilization of the plans.
Example of locality-level good practice:
Stockport MBC have set up an FASD advisory board focusing on Prevention, Assessment, Diagnosis and Support. The focus of the advisory board is: Strategic oversight of the areas for improvement as outlined in the NICE FASD quality standard; A multi-agency forum to ensure partnership working across Stockport Family and partners in working to achieve improved outcomes for children and young people pre and post FASD diagnosis; A forum to identify and seek to problem solve potential barriers to the delivery of areas of improvement; Oversight of the implemented changes, with financial planning and advise on potential funding opportunities; Support for sustainability of the implemented changes Priorities of the alcohol harm programme for 24/25 to meet the joint forward plan requirement in relation to FASD include: Ensuring AEP prevention remains a priority for the GM ICP; Implementation of AEP Prevention Pathways across all GM Maternity services; Testing potential approaches to meeting the requirements of Quality Statements 4 and 5 which relate to Neurodevelopmental Assessment and the development and implementation of Management Plans; Continued workforce development; Sustain and develop #DRYMESTER; Sustain and develop the GM FASD Network
Q8 - Via the GM FASD Network. The AEP programme was coproduced with individuals with lived experience who were involved with every aspect of the programme's design and delivery.
Q9 - Included in the GMEC Maternity Equality and Equity plan. Included in the Best Start plan (in draft).
Drymester Resources; Included in the NHS GM Joint Forward Plan
Comment from National FASD – This ICB has taken the lead nationally in establishing best practice and their response indicates the depth of their response to NICE QS 204. This ICB demonstrates the kind of systemic change that other ICBs should be exploring. That said, the ICB still has not commissioned a pathway for diagnosis. (Please note: National FASD has been awarded an 18-month contract to support continued development of the GM FASD Network.)

Commissioning Response:
C1 - NHS Greater Manchester does not currently have a formal pathway for diagnosis and management of people with FASD for children, young people, and adults within Greater Manchester.
C2 – No response
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and

management of people with FASD.

NHS HAMPSHIRE AND ISLE OF WIGHT ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This ICB did not reply by the statutory deadine.

Commissioning Response:
C1 - Yes, although none of the providers provide a FASD service in its entirety.
C2 - Solent NHS Trust do not accept referrals unless there are other reasons i.e. developmental delay. Most of these children would be medically healthy but not doing well in school which could be caused by other reasons. Hampshire Hospitals Foundation Trust offer an initial assessment and the follow up is at the consultant's discretion based on whether they have other conditions or not.
Comment from National FASD: *This ICB has not commissioned services for services for diagnosis and management of children and young people with FASD. It does however clearly state that there are avenues for assessment and care management. Families should use this response when pursuing diagnosis and support. The response was silent on adult diagnosis.*

NHS HEREFORDSHIRE AND WORCESTERSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response:
Comment from National FASD: This ICB did not reply by the statutory deadline

Commissioning Response:
C1 - The Community Paediatrician Service will provide assessment, medical care and advice for children and young people with long term conditions such as physical and learning disabilities, neuro-developmental disorders, perceptual problems and children with on-going medical needs. Under this remit, a child or young person would be seen by this service if they presented with difficulties which could be related to FASD to help understand the difficulties being experienced. H&W ICB do not commission any specific services for diagnosis and management of people with FASD.
C2 - Commissioned providers are Wye Valley NHS Trust and Herefordshire and Worcestershire Health and Care NHS Trust. H&W ICB do not hold specific pathway information or documentation.
Comment from National FASD: This ICB has not commissioned services for diagnosis and management of people with FASD. It states that the Trusts are responsible but Herefordshire NHS Trust, for example, replied, "There is no specific FASD pathway to date within our Trust. Children and young people may still be diagnosed with the condition, but it will come to light whilst they are undergoing other assessment and treatments." This shows that it is not in line with SIGN 156 which states that prenatal alcohol exposure should be "actively considered" as a cause for neurodevelopmental delay. Nor does it appear to be meeting the spirit of NICE QS 204 statements 3 and 4. It appears from the response they may make FASD as a diagnosis through their ND assessment service (it is not clear what training has been done per NICE QS 204), but have not yet committed to providing FASD specific services.

NHS HERTFORDSHIRE & WEST ESSEX ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Providers receive NICE standards directly from NICE.
Q2 - Consideration of where new/updated NICE quality standards are applicable is routinely carried out upon receipt.
Q3 - Nursing & Quality, Maternity, 0-19 Services, Paediatrics, SEND, Mental Health
Q4 - Reference to NICE quality standards are referenced where relevant in contracting documentation with commissioned providers. Consideration of applicable NICE quality standards are also made upon receipt of individual funding requests. The ICB Safeguarding Team work in partnership with Local Authority in regards Looked After Children with FASD.
Q5 - Director of Nursing and Quality. Statement 1 - Maternity units within the Hertfordshire & West Essex Local Maternity & Neonatal System; Statement 2 - As above; Statement 3 - Referrals are made by relevant health care professionals from Primary Care, Secondary Care, Tertiary Care, Community Paediatric Services,

Public Health 0-19 teams; Statement 4 - Clinical decision making around appropriateness of neurodevelopmental assessment is carried out by Community Paediatricians; Statement 5 - A management plan would be produced following diagnosis.
Q6 - To be carried out by relevant provider organisations.
Q7 - As above
Q8 - Patient experience is monitored and reported via provider organisations.
Q9 - N/A
Comment from National FASD – While it does refer to some work of the Safeguarding team and Children Looked After, this ICB's response does not indicated any changes in or plans for review of provision of service related to NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - No service specifically for the diagnosis and management of foetal alcohol syndrome commissioned.
C2 – Not applicable
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD and by its response referring only to Fetal Alcohol Syndrome demonstrates not all parts of the system are following the latest guidelines as this diagnostic term is out dated.

NHS HUMBER AND NORTH YORKSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - NHS Humber and North Yorkshire ICB can confirm that the NICE Quality Standard was shared with appropriate organisations, service providers and teams across the Humber sub-region, and the Humber and North Yorkshire Local Maternity and Neonatal System (HNY LMNS) in 2022. Stakeholders from York/North Yorkshire are engaging with the project. Providers have a responsibility for the implementation of NICE guidance and specifically the quality standards.
Q2 - The ICB can confirm that organisations, service providers and teams across the Humber and North Yorkshire region were identified as key stakeholders in the implementation of the NICE Quality Standard across the Humber and North Yorkshire Integrated Partnership (HNYICP).
Q3 - The implementation of the Fetal Alcohol Spectrum Disorder (FASD) Quality Standard is being led by the ICB's Children and Young People's Transformation Team in partnership with HNY LMNS and other key stakeholders, including local authorities (public health) teams and children's services, clinical providers including Specialist Public Health Nursing, paediatric medical and neurodiversity services and the national FASD charitable organisation.
Q4 - The ICB board members with responsibility for CYP, SEND, LD and Autism have been made aware of the system work being undertaken in the development of the FASD Pathway and Guidance aligned to the NICE Quality Standard through a presentation and it was agreed to include this project within the Humber and North Yorkshire CYP Transformation Programme, the programme formally reports to the ICB Start Well Board, which includes executive directors for inter- related programmes. The ICB does not hold the information request in relation to related documents as there are no formal papers for this work as the pathway and guidance is in the early stages of development.
Q5 - In relation to question 5. a)-e), the person with overall responsibility for activities to assure implementation with NICE Quality Standards is Teresa Fenech, Executive Director of Nursing and Quality. Providers have individual responsibility for the implementation of and adherence to NICE quality Standards.
Q6 - The ICB can confirm that it does not hold this information, as a review sheet has not been created.
Q7 - This is being led by the Humber and North Yorkshire CYP Transformation Team. Agreed leads are working with the identified stakeholders to take forward the development of the HNY FASD Pathway and Guidance aligned to the NICE Quality Standard. This work is aligned to the 4 key interdependent areas: Prevention, Early Identification, Assessment and Diagnosis, Ongoing Care. The progress of work of each area is currently variable across the ICB. For example, Hull has a FASD multi-agency training programme in place. The LMNS are using the new IMT system to include recording of maternal alcohol intake during pregnancy, supported by staff training in 'managing challenging conversations'. The aim of this work is to have an approved system-wide pathway and guidance in place by December 2024 with plans as to how each place/sub-system of the ICB will implement the quality standard in full.
Q8 - Work includes input from [a] national FASD charity (representing the voices and experiences of service users), and stakeholders are engaging with parents and carers with lived experience and bringing their views into the development work. Communication and engagement will take place with the wider group of stakeholders once the pathway and guidance is in draft format.
Q9 - No.
Comment from National FASD: This ICB states it is taking steps to ensure NICE Quality Standard 204 is being considered in relevant teams and is taking forward plans for a diagnostic pathway and implementing new coding systems for AEP. It states there is a multiagency training plan in place in some areas, but it is not clear if this is system wide. It also is not clear on plans for using

the NICE QS 204 indicators to track improvement in service over time.

Commissioning Response:
C1, C2 - NHS Humber and North Yorkshire Integrated Care Board (ICB) can confirm that it does not currently commission a specific service for the diagnosis and management of people with Fetal Alcohol Spectrum Disorder (FASD). Commissioned health services are required to support people with FASD who have identified needs including where they need support in relation to their neurodiverse, mental and/or physical health needs, as set out in the Children and Family's Act 2014, SEND Code of Practice 2014, and the NHS Constitution.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. It is not clear from the above whether they have allocated resources within their present system to better meet the needs of those with FASD.

NHS KENT AND MEDWAY ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Yes, this was shared with Provider Trusts and Local Authorities across Kent and Medway. It is the responsibility of those Trusts/Authorities to update their services/teams on the NICE Quality Standards.
Q2 - NHS Kent & Medway Children's Commissioning Team and Medway Partnership Commissioning Team are aware of the NICE Quality Standard and have shared with relevant partners.
Q3 - See above Q2.
Q4 - All of the above groups/leaders are aware of the FASD NICE Quality Standard and are taking them into account in their decision making about service provision and assessment of need. This has been via discussion at relevant meetings. There are no documents related to these discussions.
Q5 - No individual person within the ICB holds responsibility for the individual NICE Quality Standard 204. The ICB is not structured in this way and this would be the same for other Nice Quality Standards. Statement 1 - Maternity services, Community Health Visitor services and Social Care. These are delivered by various provider NHS Trusts and Local Authorities across Kent & Medway; Statement 2 - Maternity services, Community Health Visitor services, Community Paediatric Services and Social Care. These are delivered by various provider NHS Trusts and Local Authorities across Kent & Medway; Statement 3 - Any Kent and Medway Professional in Health, Social Care or Education who works with a child can discuss a referral for assessment based on the presenting needs. Referrals would make reference to presentation and concerns, including information on probable pre-natal alcohol exposure; Statement 4 - Five NHS Provider Trusts across Kent and Medway undertake neurodevelopmental assessments for children and young people. Referrals for concerns regarding FASD would be the responsibility of Clinicians within individual NHS Trusts; Statement 5 - This would be the responsibility of the NHS Provider Trust that is undertaking the assessment of the child.
Q6 - Not Applicable.
Q7 - NHS Kent and Medway have commissioned a Clinical FASD Support Service from Surrey & Borders Partnership NHS Trust to support Clinicians and other professionals working with children with FASD. This includes diagnostic support, Continuing Professional Development around FASD and support with FASD management and care plans. NHS Kent & Medway have also commissioned a suite of FASD training from an external organisation and this is open to any health, education and care staff across the system. There has also been work with colleagues from Maternity Services and Social Care, including Fostering and Adoption Teams.
Q8 - Prior to NICE Quality Standard 204 being published a there was a Kent & Medway FASD Partnership Group convened. This group included parents and carers as well as professional Clinicians, Social Care staff and Members of the local Councils. The group informed the development of FASD training offers available and developed the commissioned hub and spoke model (Surrey & Borders NHS Partnership Trust).
Q9 – No
Comment from National FASD – This ICB's response indicates it is taking action and the commissioning of services in cooperation with the FASD National Service in Surrey and efforts to improve training as called for in the NICE QS is especially encouraging. The response has not indicated any specific improvements related to Statements 1 and 2.

Commissioning Response:
C1 – a, b, c): Currently, FASD is assessed/ diagnosed/ managed by the Kent & Medway Community Paediatric services for children and young people up to 18/19 in Kent and Medway, and this is via the NHS Provider Trusts. NHS Kent and Medway have commissioned a hub and spoke clinical support service for all Kent and Medway Clinicians and other professionals (children's services) to use to support their FASD assessment, diagnosis & support/care planning.
C2 - Surrey and Borders NHS Foundation Trust are commissioned to deliver the Clinical Professional Support service to Providers in Kent & Medway for FASD.
Comment from National FASD – It is promising and exciting to see that this ICB has commissioned a hub and spoke clinical support service to support FASD assessment, diagnosis and support/care planning. We understand this is a limited offer though and we note

that it does not appear from their answer to include adults.

NHS LANCASHIRE AND SOUTH CUMBRIA ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS **Response**
Q 1 - NHS Lancashire and South Cumbria ICB does not hold this information, please redirect your request to individual Trusts: https://elht.nhs.uk/about-us/freedom-of-information; https://www.uhmb.nhs.uk/our-trust/freedom-information; https://www.blackpoolteachinghospitals.nhs.uk/services/information-governance/freedom-information-foi; https://sthk.merseywestlancs.nhs.uk/freedom-of-information-guidance; https://www.lancsteachinghospitals.nhs.uk/freedom-of-information; https://www.lscft.nhs.uk/about-us/publications-reports-policies/freedom-information
Q2 - 9 – See above
Comment from National FASD - This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning **Response**:
C1, C2 - There are no commissioned services specifically for people with FASD. Children and Young people (CYP) with FASD would be seen within the generic Community Neurodevelopmental Paediatric services which are provided by all the provider trusts in LSC. The ICB is in the process of redesigning the neurodevelopmental pathway and FASD is one of the areas that will be encompassed in that new needs led pathway.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. That said, it is encouraging to see they are including FASD in their redesign of their ND pathway and it is silent on a pathway for adults.

NHS LEICESTER, LEICESTERSHIRE AND RUTLAND ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Yes, Fetal Alcohol Spectrum Disorder (FASD) Quality Standard [QS204] has been circulated to the appropriate team within LLR ICB.
Q2 - The FASD specialist consultants sit within our community trust, and work with the Neurodevelopmental (ND) service as FASD is a differential for ND assessments and they will utilise this guidance appropriately.
Q3 - FASD sits within our community provider, Leicestershire Partnership NHS Trust (LPT) and within the wider ND pathway.
Q4 - To date, the ICB Leads have not included consideration of FASD and implementation of the Quality Standard 204 however the FASD Service is currently undergoing a scoping activity, with a consideration for the Quality Standard to be reviewed and incorporated into the service provision and assessment of local need. There currently is only 1 FASD service in the country. The East Midlands has organised a development day which is being hosted on week commencing 4 March 2024 to review the guidance to implement in line with our population needs.
Q5 – Statement 1 - Each provider has a quality schedule, and part of this refers to clinical effectiveness and NICE guidance compliance. The ICB gain assurance from provider Quality Board Meetings, and updates sort by the clinical effectiveness team, which report into both provider and ICB Quality Board Meetings. This sits within the Nursing and quality teams function but also supported by the Local Maternity and Neonatal System (LMNS); Statement 2 - The provider is responsible for ensuring each pregnant women has a physical health and well being check at booking and each antenatal appointment. This includes providing advice on diet, alcohol and smoking. The advice and any specific actions taken will be captured in the personal care plan and referrals to specialist team made as appropriate; Statement 3 - LLR ICB do not hold this information. Please be advised to redirect this request to the LPT FOI team who provide our CYP service at foi@uhl-tr.nhs.uk; Statements 4 and 5 - Yes, FASD is included within the ND assessment pathway and supported through this pathway as required.
Q6 - The FASD Team/ LLR ICB have not created a review sheet.
Q7 - LLR ICB is working with the Quality Team to assess Quality Standard [QS204].
Q8 - LLR ICB will be involving stakeholders and/ or tracking patient experiences to the NICE Quality Standard [QS204] through the scoping activity.
Q9 - LLR ICB have not created any documentation related to improvement of quality of care regarding the Quality Standard [QS204].
Comment from National FASD: This ICB is taking action, has identified an FASD service, is conducting a scoping activity that includes NICE QS 204 and there is a plan to

include in a development day. It has not identified specific steps to record alcohol exposed pregnancies. It has not verified staff have had FASD training.

Commissioning Response:
C1 - Fetal Alcohol Spectrum Disorder (FASD) Service within LLR is mainly provided for Children by Leicestershire Partnership NHS Trust (LPT) Community and Mental Health Services, however there is a strong link with the University Hospitals of Leicester NHS Trust (UHL) Maternity and Neonatal Services who support both the mother and child prenatally and postnatal linking in, where appropriate, with LPT. We are currently reviewing a number of our clinical pathways and this pathway will be reviewed in 2024/2025 as part of our Children's and Young Peoples pathway work. Adult services may identify or treat patients who have this condition, however in the first instance they would refer to a suitable specialty depending on the presenting condition.
C2 - LPT and UHL provide the FASD service to Children and Young People. At present, there are no relevant documents in relation to the FASD service.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD though it has indicated this can be undertaken via existing pathways. Families seeking diagnosis should quote this response.

NHS LINCOLNSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
✗	✗

NICE QS Response
Please note it is not the responsibility of the ICB to cascade NICE quality standards, there will be a national process for that. We would expect our providers to review and consider NICE guidance and quality standards via their quality committees and professional practice groups. We have provided some information below.
Q1 - United Lincolnshire Hospital's NHS Trust (ULHT) has seen this quality standard.
Q2 - This is applicable to ULHT, see response to Q1.
Q3 - As Q1 and 2.
Q4 - Not held.
Q5 – Statements 1 and 2 - All midwives give advice on alcohol in pregnancy and record consumption on the MIS at every appointment; Statements 3, 4 and 5 - No current lead. Would need to review the guidance and determine.
Q6 - Not held.
Q7 - ULHT have formally reviewed the quality standard and the trust considers itself compliant with the relevant statements.
Q8 – Not held.
Q9 – Not held.
Comment from National FASD - This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1: a) no; b) no; c) no
C2: n/a
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS MID AND SOUTH ESSEX ICB

Nice Quality Standard 204 Improvements	Commissioning
✗	✗

NICE QS Response
Q1 - Providers are responsible for circulation to the services which they provide.
Q2 - Providers are responsible for considering applicability of these standards.
Q3 - Maternity and Neurodevelopmental Service Leads within ICB and Maternity with acute Trusts.
Q4 - We do not specifically note FASD as this is a cause of neurodevelopmental issues, but we commission services to support people with neurodevelopmental issues
Q5 - Under section 40 (2) of the Freedom of Information Act 2000, a public authority does not have to provide information where that information is considered personal information under the Data Protection Act 2018. We believe that the names you have requested falls into this category, and therefore will not be supplying this as a result. Guidance states that personal information can be released where it is deemed the staff member in question is either public facing or senior/decision making. ICB has taken the decision that this solely refers to board members, whose details are available on our website. Responsibility for NICE Quality Standard 204 statement within the ICB sits with the Director Children Mental Health & Neurodiversity and for Maternity falls under Consultant Midwife. Statement 1 - It is routine practice to discuss the risks of alcohol in pregnancy and to enquire about alcohol use at the initial 'booking' appointment, and this is documented routinely as part of the booking records. All women are advised against alcohol use in pregnancy. If a person

discloses that they are still drinking alcohol, they can be referred for specialist support and an ongoing plan of care with a Substance Misuse Midwife at MSEFT; Statement 2 - Unless the woman or birthing person has disclosed that they were still consuming alcohol at the booking appointment, routine enquiries are not made at every antenatal appointment. Women and birthing people who have been referred for support and care by the Substance Misuse midwife will be asked about their alcohol use and supported throughout their antenatal care; Statement 3 - There is no local assessment service – if assessment required, an IFR request is made and considered for a referral to a specialist service. In the maternity service, all new-born babies are examined at birth by the midwife, and also receive new-born and infant physical examination (NIPE) within 72 hours of birth. Whilst the main purpose of the examination programme is to identify and refer all children born with congenital abnormalities of the eyes, heart, hips and (in males) testes, the overall aim is to reduce morbidity and mortality. Doctors and midwives who are qualified to undertake the NIPE are trained to take maternal, antenatal, and family history into consideration, and perform a thorough physical examination. If there is any concern about facial features, a referral would be made for review by a more senior Paediatrician; Statement 4 - Any baby who has been referred for assessment by a Paediatrician or Neonatologist will have an individualised management plan, which will include follow up and ongoing referrals as appropriate. You can seek further information from the neonatal service (MSEFT); Statement 5 - Part of usual management of patients with neurodevelopmental disorders.
Q6 - No specific NICE leads - responsibility sits with relevant commissioner.
Q7 - Quality standards play a key role in helping commissioners and providers and support us to: support in identifying changes that need to be made in order to develop services; empower providers to ask for the specific support they need to improve service performance and quality; provide commissioners with key quality markers that they can include in service specifications.
Q8 - This might be something that the Substance Misuse midwives at the Trust could answer.
Q9 – No
Comment from National FASD - This ICB has not demonstrated it is taking action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision. The response has not indicated any FASD-specific training as called for in NICE QS 204, the response regarding Statement 2 is not compliant with the QS call for discussion throughout the pregnancy and they have stated there is no local assessment for FASD available and have not identified plans to put this in place. While they say they are taking information in booking interviews, who reviews those records to see whether the rate of alcohol intake is going up or down? There is no indication improvements over time are being tracked using NICE QS 204 indicators.

Commissioning Response:
C1 - No. Drug and alcohol were transferred through to the local authorities via public health and now sits Essex County Council
C2 – N/a
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS NORFOLK AND WAVENY ICB

Nice Quality Standard 204 Improvements	Commissioning
✓	–

NICE QS Response
Q1 - Following publication of the NICE quality standard and a subsequent Freedom of Information request Norfolk and Waveney ICB completed a review of FASD in 2022/23 and therefore shared with stakeholders as part of a data gathering exercise.
Q2 - The quality standard would sit across Maternity, Healthy Child programme and Neurodevelopmental pathways.
Q3 - Local authority public health teams; Local acute and community trusts; Local maternity and neonatal system.
Q4 - Patricia D'Orsi, Executive Director for Nursing is the ICB named board member responsible for a-d. The CYPM team, which includes CYP, SEND, Safeguarding and LD&A has considered how this quality standard should and could be implemented within services. This team is systematically reviewing all service specifications to ensure they reflect all relevant quality standards. The attached slide deck suggests that the new quality standard should be considered within a broader review of the neurodevelopmental service offer in the Norfolk and Waveney system.
Q5 - Children, Young People and Maternity Commissioning team; Statement 1 and 2 - All pregnant women are screened for alcohol consumption/misuse during the initial booking appointment with the community midwife. They will be asked about how many units they consumed prior to pregnancy and if they are abstaining. All pregnant women/birthing women will be advised not to drink alcohol during pregnancy and the associated risks. If they are suffering from alcohol dependency, they will be referred to the vulnerable women's/ substance misuse teams. Currently, data regarding the provision of alcohol in pregnancy information and the prevalence of alcohol misuse in pregnancy is not routinely collected.
Statement 3 - Consultant community paediatrician advise most concerns come from local authorities, adoption support, social workers or estranged parents. In these circumstances the issue and proof of prenatal alcohol exposure is quite difficult to ascertain. Most of these children are referred due to complex learning and

behavioural patterns. Other community paediatricians agreed that their referrals come from the same places, and it is very rare for birth parents to seek an FASD diagnosis. Statement 4 - Consultant Paediatrician advised she had never received a referral based on facial features alone and the identification of the facial features is a contentious area with differing criteria in the UK, Canada and Australia. All 3 acute trusts have the same process. Referral received, developmental history taken and investigated if required with genetic testing. If clinical features, history and the child's needs add up a diagnosis of FASD is given. If clinically indicated a neurodevelopmental assessment is undertaken. Statement 5 - James Paget University Hospital only follows up if sleep medication is being used and only by video clinic. ASD diagnosis discharged and signposted to voluntary sector advice and support services. ADHD followed up in ADHD clinic. ASD & ADHD follow up process the same in all 3 acute trusts. Consultant paediatrician feels services should not separate the different 'labels' into different services and all children with NDD or FASD should receive the same offer of support. NDD pathways should be all encompassing including developmental trauma, ASD, ADHD and FASD.
Q6 - N/A
Q7 - Recommendations following the review include but are not limited to: Joint working of midwives and substance misuse teams with more targeted work. Alcohol use in pregnancy should be recorded routinely. Babies admitted to neonatal are flagged on Badgernet as neonatal abstinence syndrome – Badgernet can be filtered, and these children could be seen in a community paediatric clinic the same way children who require a Bayleys assessment are seen (children requiring Bayleys are offered an appointment at 2 years of age, clinicians in the assessment of FASD would need to specify when an assessment would be required.) Children at risk of removal for substance misuse should be referred to health services by local authorities. If clinically indicated children are seen for a neurodevelopmental assessment. Neurodevelopmental pathways should be inclusive of FASD and there should be psychology input for cognitive assessments. Children with FASD should be followed up and there should be a support offer for all Neurodiverse children. Children with FASD should receive the right support at the right time.
Q8 - Throughout initial review of provision, we have engaged with Consultant community paediatricians and neurodevelopmental assessment services, midwifery teams and shared the review outcome with local stakeholder groups who include representatives from local authority, health, care and VCSE organisations.
Q9 - Please see attached. [Powerpoint included in response.]
Comment from National FASD – This ICB has conducted a review, including stakeholders, and has outlined some recommendations for addressing the QS statements that seem positive. It's not clear if they have yet identified training that needs to be done to ensure the NICE QS recommendations on training are being met.

Commissioning Response:
C1a, C1b - Identification of children and young people at risk of FASD sits within services across Maternity, the Health Child programme and Neurodevelopmental pathways. Consultant community paediatricians advise most concerns come from local authorities, adoption support, social workers or estranged parents. Most of these children are referred due to complex learning and behavioural patterns. If clinically indicated, children are seen for a neurodevelopmental assessment. Neurodevelopmental pathways should be inclusive of FASD and there should be psychology input for cognitive assessments. All commissioned services are subject to periodic review and the new Quality Standard for FASD will be included at the next refresh.
C1c - There is no service for adults
C2 - Neurodevelopmental assessments are provided by two main trusts in Norfolk, Norfolk Community Health and Care and James Paget University Hospital. Children and young people in Thetford are usually referred to Suffolk Integrated Community Paediatrics Services.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD, but it has indicated that FASD diagnosis for children and young people 'should' be included in existing pathways. This statement should be shared by families if they encounter problems seeking FASD diagnosis and care management. It states that diagnosis for adults is not commissioned. It is encouraging to hear that a review of NICE QS 204 is to be included in their next refresh.

NHS NORTHAMPTONSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
✗	✗

NICE QS Response
Q1 - For maternity services, the quality standard was circulated by the Royal College of Obstetricians & Gynaecologists as well as through the trusts' normal NICE governance processes.
Q2 - Not held
Q3 - Re Statements 1 and 2 below, these are applicable to maternity services at Northampton General Hospital NHS Trust and Kettering General Hospital NHS Foundation Trust.
Q4 - Not held
Q5 – Statements 1-2 - compliance with all NICE guidance and Quality Standards is part of the Maternity Contract; Statement 3 - As above; Statement 4 – Not held; Statement 5 – Not held.
Q6 - Not held
Q7 - Not held
Q8 - Not held

Q9 - Not held
Comment from National FASD - This ICB has not demonstrated it is taking specific action on NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1 - The ICB does not have a specifically commissioned service for Fetal Alcohol Spectrum Disorder. However, the paediatricians commissioned by the ICB from Northamptonshire Healthcare NHS Foundation Trust (NHFT) or Northampton General Hospital NHS Trust (NGH) will pick up on issues if it is in relation to issues community paediatrics are reviewing.
C2 - Not applicable
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS NORTH EAST AND NORTH CUMBRIA ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - 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.
Q2 -- 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.
Q3 – See above
Q4 - 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.
Q5 – Statement 1 - 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; Statement 2 - 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; Statement 3 - Depending upon the presentation and age of the child they would either be referred to community paediatrics, Neurodevelopmental pathways or CAMHS for an assessment; Statement 4 - 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; Statement 5 - CYP with a diagnosis of FASD will have a management plan but as above in 4 this may vary across trusts/places.
Q6 - 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.
Q7 – See above
Q8 – See above
Q9 - Please find attached, copies of relevant documents. [North East England Alcohol in Pregnancy Maternity Pathway and Audit C]
Comment from National FASD – This ICB is taking action to respond to NICE Quality Standard 204 with a task and finish group underway. A diagnostic pathway is being considered and they have taken steps to have training and pathways in place regarding alcohol and pregnancy. It recognises there is still patchy provision.

Commissioning Response:
C1 - North East and North Cumbria does not commission the services for diagnosis and management of people with FASD. However diagnostic pathways are in place across the ICB's geographical area. This information is likely held by the Acute Trusts who can be contacted at the following: County Durham & Darlington NHS FT; Gateshead Health NHS FT; North Cumbria Integrated Care NHS FT;
North Tees & Hartlepool NHS FT; Northumbria Healthcare NHS FT; South Tees Hospitals NHS FT; South Tyneside and Sunderland NHS FT; The Newcastle Upon Tyne Hospitals NHS FT
C2 - Please see attached pathway [for alcohol in pregnancy]
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. Its response shows

the confusion that can exist even across a limited area on these issues.
South Tees said, "The Community Child Health team are currently working with commissioners and other specialists such as psychology re developing a specific pathway for FASD. This will be a multiagency approach and is in its early stages, the pathway will be reviewed and details shared with parent/carer groups for review." South Tyneside and Sunderland said, "The ICS is leading implementation of NICE QS 204 via an FASD task and finish group and mentions steps toward a regional strategy, a neurodevelopmental pathway which includes development of regional support for diagnoses more difficult cases." Newcastle Upon Tyne said, "System-wide work is currently underway in Newcastle-Gateshead, by a FASD working group (including partners from Mental Health Services, Local Authorities, Foundation Trusts and colleagues from the North East and North Cumbria Integrated Care Board), to submit a proposal to operationalise standard assessments and recommendations to children and young people affected by alcohol in utero across the locality." Durham and Darlington NHS Trust says "We do not have the resources in Community and Neurodevelopmental Paediatrics to make a management plan for a child's needs, unless these are related to a specific health condition such as epilepsy." Gateshead, North Tees & Hartlepool didn't reply by the statutory deadline. North Cumbria, Northumbria stated FASD diagnosis is not commissioned. It is not clear what is in place for diagnosis and support of adults.

NHS NORTH CENTRAL LONDON ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - NHS North Central London ICB does not circulate NICE guidance and quality standards to our providers. Each provider will have their own process to review, disseminate and implement NICE guidance and quality standards.
Q2 - Each provider will have their own process to review, disseminate and implement NICE guidance and quality standards.
Q3 - Each provider will have their own process to review, disseminate and implement NICE guidance and quality standards.
Q4 – *[This question was not asked of 5 London ICBs who received the initial test request. The other response question numbers have been adjusted to match the rest of the requests.]*
Q5 – Statement 1 - Our maternity units in North Central London Local Maternity and Neonatal System (LMNS) have their own policies and processes in place regarding the communication and embedding of new guidance. For example, the NICE Antenatal Care Guidance (NC201) and NICE Pregnancy and Complex Social Factors (CG110) which focus on alcohol use, avoidance and referral pathways have been embedded for a substantial period; Statement 2 - Our maternity units in North Central London LMNS have their own policies and processes in place regarding the communication and embedding of new guidance. For example, the NICE Antenatal Care Guidance (NC201) and NICE Pregnancy and Complex Social Factors (CG110) which focus on alcohol use, avoidance and referral pathways have been embedded for a substantial period. It also needs to be noted that maternity units within North Central London LMNS have well established vulnerable women's teams to support disclosure; Statements 3 – 5 - We are unable to comment on this aspect of care, as this sits with the individual NHS Trusts who have their individual policies and processes in relation to this aspect of care.
Q6 - No. The ICB has not created a review sheet in relation to the quality standard structure, process and outcomes measures, as each provider will have their own process to review, disseminate, implement and evaluate NICE guidance.
Q7 - We are unable to comment on this aspect of care, as each provider will have their own process to review, disseminate and implement NICE guidance.
Q8 - We are unable to comment on this aspect of care, as each provider will have their own process for involving stakeholders and / or tracking patient experiences.
Q9 - No. The ICB has not created a document in relation to quality of care regarding the NICE standard, as each provider will have their own process to review, disseminate, implement and evaluate NICE guidance.
Comment from National FASD - This ICB has not demonstrated it is taking specific action on NICE QS 204. It appears to have an expectation that the constituent members of their area will be doing something. Perhaps they should have an area-wide ability to check what is happening?
It's interesting that they are commissioning something but not checking whether the areas they are commissioning are actually following NICE QS 204.

Commissioning Response:
C1, C2: NHS North Central London ICB has commissioned the providers listed in the table below. Barnet/Camden - Royal Free London NHS Foundation Trust; Enfield - North Middlesex University Hospital NHS Trust; Haringey/Islington - Whittington Health NHS Trust. Pathway - NHS North Central London ICB does not hold this information. Please contact the providers listed below directly for this information.
Comment from National FASD – It is encouraging to know that this ICB has commissioned 3 Trusts to diagnose and support FASD but we have not been able to verify that from the Trust responses. Royal Free London's FOI request had a delivery error so we did not receive a reply from them; North Middlesex University Hospital Trust did not reply by the statutory deadline. Whittington Health Trust's reply said they did not hold

information about commissioning and that we should contact the ICB, and their reply indicated that are not taking action following NICE QS 204 to improve quality of services and still wrongly believe that FASD is a 'rare' condition.

NHS NORTH EAST LONDON (NEL) ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - The standard has been distributed to the providers across NHS NEL and we are seeking assurances as to how they are implementing this standard.
Q2 - Yes.
Q3 - Local Maternity and Neonatal System (LMNS), Primary Care, Babies, Children and Young People (BCYP), Safeguarding and Mental Health Services.
Q4 – *[This question was not asked of 5 London ICBs who received the initial test request. The other response question numbers have been adjusted to match the rest of the requests.]*
Q5 – Statement 1 - LMNS and Primary care. The LMNS would liaise and support the maternity providers; Statement 2 - LMNS and Primary care. The LMNS would liaise and support the maternity providers. Data would be captured at Trust level but not an MSDS requirement; Statement 3 - BCYP, Primary Care (Health visitors/GP's); Statement 4 - BCYP, Primary Care (Health visitors/GP's); Statement 5 - BCYP .
Q6 - The ICB does not have this role.
Q7 - The ICB will be seeking assurances from the relevant providers across NHS NEL, as to how they are responding to this Quality Standard through the LMNS.
Q8 - Primarily, the LMNS would work with Maternity Neonatal Voice Partnership (MNVP) chairs to seek service user experience across NHS NEL.
Q9 – N/A
Comment from National FASD – This ICB has taken some initial steps to distribute NICE QS 204 and identify relevant services. It has not indicated it has taken any action specific to improving quality of care based on NICE QS 204 and the response is silent on any training as called for in the QS so it is unclear if the LMNS and other services are able to respond to the SIGN 156 guidelines and QS statements.

Commissioning Response:
C1, C2 - NHS NEL ICB does not hold this information or report on this level of detailed requested. As We do not commission this service for any age group. You may wish to resubmit your request to the Trusts, who may hold this information: https://www.nhs.uk/service-search/hospital
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS NORTH WEST LONDON ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 – This would not be an ICB role. Each trust is accountable for responding to NICE guidance.
Q2 – This would not be an ICB role. Each trust is accountable for responding to NICE guidance.
Q3 – The Local Maternity & Neonatal System brings together maternity service providers and the ICB, including a foetal medicine network.
Q4 – *[This question was not asked of 5 London ICBs who received the initial test request. The other response question numbers have been adjusted to match the rest of the requests.]*
Q5 - These would not be ICB roles. Each trust is accountable for responding to NICE guidance.
Q6 - Not applicable
Q7 - Foetal medicine network discusses necessary update.
Q8 - MNVP chairs - (Maternity & Neonatal Voices Partnerships).
Q9 - Not applicable.
Comment from National FASD - This ICB has not demonstrated it is taking specific action on NICE QS 204.

Commissioning Response:
C1, C2 - The ICB has not commissioned specific fetal alcohol spectrum disorder services. Treatment would be though our main NHS Trusts current services.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD but states this is the responsibility of Trusts. Families should note this response in seeking diagnosis and support via the local Trusts.

NHS NOTTINGHAM AND NOTTINGHAMSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This ICB did not reply by the statutory deadline.

Commissioning Response
C1 - No, the ICB has not commissioned services for diagnosis and management of people with Fetal Alcohol Spectrum Disorder.
C2 – Not applicable
Comment from National FASD: *This ICB has not commissioned services for services for diagnosis and management of people with FASD.*

NHS SHROPSHIRE, TELFORD AND WREKIN ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD – This ICB did not reply by the statutory deadline.

Commissioning Response
Comment from National FASD – This ICB did not reply by the statutory deadline.

NHS SOMERSET ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - The NICE Quality Standard 204 has been circulated to our providers.
Q2 - Our providers through their own governance arrangements would identify which areas of their service are applicable.
Q3 - Please refer to the response to Question 2.
Q4 - Somerset ICB leads in each relevant team have been sighted and are aware that we are not compliant with this new NICE standard as there is not currently a multi-disciplinary team (MDT) pathway in place. This will now be addressed in due course.
Q5- The responsibility of implementing NICE standards sits with the providers of these services. Statements 1 and 2 - Responsibility sits with our maternity provider - Somerset NHS Foundation Trust; Statement 3 - Responsibility sits with our maternity provider - Somerset NHS Foundation Trust. Statements 4 and 5 - Responsibility sits with our community paediatrics provider – Somerset NHS Foundation Trust.
Q6 - Somerset ICB does not currently have a review sheet.
Q7 - We share recommendations with our providers.
Q8 - We are not currently involved in this.
Q9 - Not at this time, policies and guidance would sit with the providers of these services.
Comment from National FASD - *This ICB has not demonstrated it is taking specific action on NICE QS 204.*

Commissioning Response**:**
C1 – a, b, c): We currently do not specifically commission pathways for adult or children with FASD. However, children with suspected FASD will be referred through the community paediatric service if under 5 years, or through our children and young people (CYP) neurodevelopmental pathway if over 5 years.
C2 – n/a
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS SOUTH EAST LONDON ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 -
No – this hasn't been specifically circulated by the ICB but we are aware that each of our NHS trusts have a formal routes in place to receive the latest NICE guidance.
Q2 - Not to date. The ICB holds commissioning responsibility for maternity services (including perinatal care which covers advice/guidance on alcohol during pregnancy) and assessment, diagnosis, and treatment of neurodevelopmental disorders for children, young people and adults, and therefore the standard would be

applicable. Our individual NHS trusts are responsible for completing their own assessments of NICE Quality Standards through their own internal clinical governance routes.
Q3 - A formal assessment has not been carried out however the Standard would be relevant to the ICB and our providers of maternity services and neurodiversity services.
Q4 – *[This question was not asked of 5 London ICBs who received the initial test request. The other response question numbers have been adjusted to match the rest of the requests.]*
Q5 – Statements 1-5 - Responsibility for the NICE Quality Standard within our ICB would be our SRO for Maternity and our ICB Board CYP Lead. This is currently our ICB Chief Nurse.
Q6 - Not applicable – this work has not been carried out to date.
Q7 - The ICB will work through relevant partners including its Local Maternity and Neonatal System, the Community Provider Network and our Local Care Partnerships to understand how this Quality Standard applies to the services we are responsible for commissioning. We are yet to agree a timeline for this work.
Q8 - Not applicable – this work has not yet been completed.
Q9 - None
Comment from National FASD - This ICB has not demonstrated it is taking specific action on NICE QS 204.

Commissioning Response:
C1, C2 - Within South East London ICB we do not commission a bespoke service for FASD in adults, children and young people (CYP). The diagnosis, assessment and care of FASD spans primary care, maternity services, neonatal services, community paediatrics and mental health services. Across South East London we have various training and awareness courses in place for professionals to identify FASD, and we have neurodiversity services for CYP and adults across south east London with clear referral pathways for professionals.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS SOUTH WEST LONDON ICB

Nice Quality Standard 204 Improvements	Commissioning
✗	✗

NICE QS Response
Q1 – 3 and Q 5-9 - The ICB does not hold this information. You may wish to redirect your request to the relevant NHS Trusts, who may hold this information. The contact details are: Croydon Health Services NHS Trust, Freedom of Information | Croydon Health Services NHS Trust; Kingston Hospital NHS Foundation Trust Freedom of Information - Kingston Hospital; Epsom and St Helier University Hospitals NHS Trust Freedom of information (FOI) at Epsom and St Helier hospitals | Epsom and St Helier University Hospitals (epsom-sthelier.nhs.uk); St George's University Hospitals NHS Foundation Trust Freedom of Information - St George's University Hospitals NHS Foundation Trust (stgeorges.nhs.uk); Hounslow and Richmond Community Healthcare NHS Trust Freedom of Information :: Hounslow & Richmond Community Healthcare (hrch.nhs.uk); The Royal Marsden NHS Foundation Trust Freedom of information | The Royal Marsden
Q4 – *[This question was not asked of 5 London ICBs who received the initial test request. The other response question numbers have been adjusted to match the rest of the requests.]*
Comment from National FASD - This ICB has not demonstrated it is taking specific action on NICE QS 204.

Commissioning Response:
C1, C2 - The ICB does not hold this information. South West London ICB does not specifically commission any FASD services.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS SOUTH YORKSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
✓	✗

NICE QS Response
Q1 - This has been presented at the Local Maternity and Neonatal System (LMNS) Healthy Lifestyle Working Group and circulated with the minutes (1st Feb 2024). This group has representation across health and social care, maternity and 0-19 services. The LMNS team will be working with Trusts to embed these conversations into every contact.
Q2 - Yes as per Response 1
Q3 - Yes as per Response 1
Q4 - FASD has been considered as part of the MHLDA provider collaborative system work on transformation neurodevelopmental assessment and is an agenda item as part of the monthly steering group meetings.
Q5 – Statement 1 - The LMNS team has responsibility via Prevention Work. We also link in with the South Yorkshire FASD Steering Group; Statement 2 - As per Response 5a; Statement 3 - This is part of the One Adoption FASD work taking place and is linked to the

answer in Response 4; Statement 4 - As per Response 4; Statement 5 - We are working towards this aim, please see Response 4.
Q6 - We do not have a review sheet, please see Response 1.
Q7 – Please see Response 1.
Q8 – Please see Response 1.
Q9 - No other document has been created.
Comment from National FASD – This ICB is taking some action, as they say FASD is considered in monthly steering group meetings of the mental health, learning disability and autism provider system. They also say they link with South Yorkshire FASD Steering Group. However their response does not indicate training across their ICB as called for in NICE QS 204 and without training it is difficult to ensure that the MHLDA system is adequately prepared to undertake the improvements called for in NICE QS 204. The ICB has failed to recognise that the responsibilities of specific board members in their ICB are meant to include consideration of FASD and NICE QS 204 in decisions of service provision.

Commissioning Response:
C1, C2 - Currently there are no specific services commissioned by NHS South Yorkshire ICB for the diagnosis and management of people with FASD for any age group. We would expect this condition to be picked up through paediatric pathways where the presentation would be related to developmental/neurodevelopmental delay, and would potentially include genetic testing for other diagnoses etc.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD.

NHS STAFFORDSHIRE AND STOKE-ON-TRENT ICB

Nice Quality Standard 204 Improvements	Commissioning
✗	✗

NICE QS Response
Q1 - 3 - This information is not held by the ICB.
Q4 - a) Children and Young People (1 to 25) – Chief Transformation Officer; b) Children and Young People with special educational needs and disability –Chief Transformation Officer; c) Safeguarding (all ages) – Chief Nursing and Therapies Officer. Yes, considered within the FASD workstream, led by the Local Authority which Safeguarding personnel attend. Your request should be sent to the Local Authority who will hold these documents. Contact details below:
Staffordshire County Council
https://www.staffordshire.gov.uk/Your-council-and-democracy/Request- and-access-information/Request-and-access-information.aspx
Stoke-on-Trent City Council
https://www.stoke.gov.uk/info/20032/our_data/153/freedom_of_information_requests; d) Learning Disability and Autism (all ages) – Chief Transformation Officer.
The ICB does not have a local assessment of need or specific service provision for FASD.
Link to the Board members is publicly available at: Board members Archive - Staffordshire and Stoke-on-Trent, Integrated Care Board (icb.nhs.uk)
Q5 – Statement 1 - Please see response to question one; Statement 2 - Please see response to question one; Statements 3 – 5 - The ICB does not commission a specific pathway for FASD and CYP's are supported within community paediatric services and if a further assessment is required refer to a specific clinic. Please redirect your request to the following Providers: University Hospitals of Derby and Burton NHS Trust; University Hospitals of North Midlands NHS Trust; Midlands Partnership University NHS Foundation Trust
Q6 – 8 - Please see response to question one.
Q9 - No one specific document but promoting the health of pregnant women is included in many documents and action plans.
Comment from National FASD – This ICB has said in its reply it does not have a local assessment of need or specific service provision for FASD. It has not indicated any identified improvements in quality of its services in light of NICE QS 204 and has not indicated any training is being conducted as called for in NICE QS 204.

Commissioning Response:
C1 - The ICB does not commission a specific pathway for FASD and Children and Young People (CYP) are supported within community paediatric services and if a further assessment is required refer to a specific clinic. Please redirect your request to the following Providers: University Hospitals of Derby and Burton NHS Trust; University Hospitals of North Midlands NHS Trus;; Midlands Partnership University NHS Foundation Trust
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. University Hospitals of Derby and Burton are not taking action on Statements 3-4; University Hospitals of North Midlands and Midlands Partnership University NHS Foundation Trust did not reply by the statutory deadline.

NHS SUFFOLK AND NORTH EAST ESSEX ICB

Nice Quality Standard 204 Improvements	Commissioning

NICE QS Response
Q1 - Please see attached communication which was sent to the GP's across the ICB which details the NICE guideline. This was also sent to Acute Trust colleagues and discussed within the maternity led preterm birth prevention workstream
Q2 - Not been asked, but been educated through the attached briefing. Also launched a preconception education video for all stakeholders which includes information about FASD, but not specifically the NICE guidance
Q3 - Primary care, paediatrics, maternity, neonatal, health visiting and children's services, Turning Point and Open Road.
Q4 - Maternity (Lisa Nobes SRO) has, through the approval of preterm prevention pathway at the LMNS Strategic Group which
includes prevention/preconception element.
Q5 – Statements 1 - 5 - Suffolk and North East Essex do not have someone in this position, this would sit with the providers. Please redirect your request to the below trusts: Freedom of information - East Suffolk & North Essex NHS Foundation Trust (esneft.nhs.uk); Freedom of information (wsh.nhs.uk); Freedom of Information Publication Scheme | Norfolk and Suffolk
NHS (nsft.nhs.uk); Freedom of Information | NELFT NHS Foundation Trust
Q6 - n/a
Q7 - Provided awareness campaign through attached briefing, including in clinical pathway which ICB is implementing with maternity providers, joint GP campaign with Essex public health, awaiting Suffolk public health to complete their area, education package - [26]Preconception Training for
System Partners - Suffolk and North East Essex Wellbeing Support Services (sneewellbeing.org.uk)
Q8 - Not at that stage yet
Q9 - See attached and link above
Comment from National FASD – This ICB is taking action across most of the Statements and that is encouraging, particularly its efforts to reach GPs with information about NICE QS 204 and their use of the Drymester campaign to raise public awareness. It is not clear from their response if they have commissioned FASD diagnosis or what training is underway to ensure awareness is across services and that the maternity teams have needed training.

Commissioning Response:
C1, C2 - We do not commission a set pathway, however, community paediatric services will diagnose a child in the first few years of life as part of the normal service but that is all we have.
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. While the response states that community paediatrics will diagnose in first few years of life, the neurodevelopmental assessments needed cannot be done on children that young so this will likely only capture less than 10% of those with FASD who have sentinel facial features. This would not meet NICE QS 204 so we consider this ICB to not have demonstrated commissioning for FASD diagnosis and management.

NHS SURREY HEARTLANDS ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This ICB did not reply by the statutory deadline.

Commissioning Response:
C1 a) Yes; b) Yes (Surrey and Borders Partnership NHS Foundation Trust (SABP) assess for children and adults, Young People will fall within this however there doesn't seem to be a separate pathway for "Young People" once 18, an individual will be assessed via the adult's pathway and 6-17 will be assessed via the children's pathway). For most accurate detail, please redirect to SABP for further information; c) For adults – not commissioned locally.
C2 - Surrey and Borders Partnership NHS Foundation Trust (SABP), FASD: Surrey and Borders Partnership NHS Foundation Trust (fasdclinic.com). For most accurate detail referring to the pathway, please redirect to SABP for further information.
Comment from National FASD: This ICB has perhaps the premiere pathway for FASD diagnosis in the country (please see information about the clinic in the Hub and Spoke Model section of this report). The Surrey national clinic however, does not offer care management and the response is silent on that part of the questions while highlighting there is no pathway for adults.

NHS SUSSEX ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Providers, Commissioners, Programme Leads and Quality Team are in receipt of the quality standard. The Quality standard has also been circulated to contracting leads.
Q2 - 3 - FASD consideration is included in service specifications for contracted providers (currently in draft form) and compliance is monitored through contracting mechanism.
Q4 - FASD consideration is included in service specifications for contracted providers (currently in draft form). Referral routes to the specialist centre at Redhill has been shared with lead CDC paediatricians. Funding is through LVA. The NICE standards are being discussed with local providers to ensure they are embedded into clinical pathways.
Q5 – Statement 1 - Advice about alcohol use in pregnancy is included as an element of the maternity service specification; Statement 2 - Conversations about alcohol use in pregnancy are included as an element of the maternity service specification; Statement 3 - G.P referral route is to local CDC paediatricians who screen the referral and organise local diagnostics, the pathway is triggered to specialist centre at Redhill accordingly. Fetal Alcohol Spectrum Disorders Clinic: Surrey and Borders Partnership NHS Foundation Trust (sabp.nhs.uk) Please contact provider organisations for local pathways of care documentation. SCFT Seaside View Child Development Centre, (sussexcommunity.nhs.uk), ESHT Child development clinic – East Sussex Healthcare NHS Trust (esht.nhs.uk); Statement 4 - CYP with FASD features are referred for assessment to include NDC screening; Statement 5 - Please contact provider organisations for management plans / care documentation.
Q6 - The assurance the LMNS have received is as follows: UHSx: 1. Have a 'One Stop' clinic in place which provides an MDT clinic that also includes relevant partners from across the system; 2. The Nice quality standard is incorporated into the Antenatal Care Guideline. ESHT: 1. Antenatal guideline references asking about alcohol intake; 2. Recent investment will improve their current pathway by training support workers to aid with supportive conversations & early identification of those who may need additional, specialist input. NHS Sussex have a review process in place which includes use of the NICE supporting tools and an assurance template being discussed at contracting meetings with providers. However, this process was not fully developed/implemented in March 2022 (when NICE Quality Standard 204 was published.)
Q7 - N/A
Q8 - The ICB are not tracking individual level patient experiences in relation to this NICE Quality Standard.
Q9 - Please refer to NICE supporting tools. Fetal Alcohol Spectrum Disorder consideration is included in service specifications for contracted providers (currently in draft form).
Compliance will be monitored through contracting mechanism and QRMs

Comment from National FASD: The ICB states it is compliant with Statements 1 and 2 but the response is silent on training as called for in NICE QS 204. They seem to rely on diagnosis via the national FASD Clinic in Surrey, but have not specified development of local diagnostic services. They state that they are including FASD in service specifications which is encouraging.

Commissioning Response:
C1 - No. FASD assessments are carried out by the FASD clinic, part of Surrey and Borders Partnership Trust. Sussex GPs will refer directly to the clinic who will carry out assessments with no additional funding or commissioning requirements from Sussex ICB based on Low Volume Activity block payment arrangements.
C2 - For the FASD pathway relating to Adults Mental Health, please redirect this request to Partnership NHS Foundation Trust.
Comment from National FASD: While this ICB states it does not commission for FASD diagnosis and management, the response indicates funding is in place for referral to the Surrey Clinic for diagnosis. It is Interesting that they are still regarding the need as a low volume need despite statistics that show FASD affects 2-4% of the population. The Surrey clinic does not provide care management so Statement 5 is not met in any event.

NHS WEST YORKSHIRE ICB

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This ICB did not reply by the statutory deadline.

Commissioning Response:
C1 - No. Work has started on developing and coordinating a West Yorkshire approach for diagnosis, care pathways and support for children and families affected by FASD and a working group is being established to drive this forward.
C2 - Not applicable
Comment from National FASD: This ICB has not commissioned services for services for diagnosis and management of people with FASD. It is encouraging however that they are establishing a working group to move forward FASD diagnosis, care pathways and support.

HEALTH BOARDS (WALES)

QUESTIONS ASKED OF WELSH HEALTH BOARDS

NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder was published 16 March 2022 (https://www.nice.org.uk/guidance/qs204)

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

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

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

4. Please indicate who in your Health Board has responsibility for each NICE Quality Standard 204 statement:
4a. Statement 1: Advice on avoiding alcohol in pregnancy (Pregnant women are given advice throughout pregnancy not to drink alcohol.)
4b. Statement 2: Fetal alcohol exposure (Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded)
4c. 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.)
4d. 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.)
4e. 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.)

5. 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.

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

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

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

Health Boards were then sent a second question:

1. Has your Health Board commissioned services for diagnosis and management of people with FASD (Fetal Alcohol Spectrum Disorder)
a) For children
b) For young people
c) For adults

2. If yes, please say who has been commissioned to do this and what the pathway is, and provide any relevant documents.

HEALTH BOARDS - DETAILED RESPONSES

Aneurin Bevan University Health Board

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response

Q1 - Yes, this quality standard been circulated to staff within Maternity, Paediatrics and Children and Adolescent Mental Health Services (CAMHS).
Q2 - Yes, teams or other organisations within our Health Board been asked to identify whether NICE Quality Standard 204 is applicable to our service.
Q3 - Teams/organisations which have identified that NICE Quality Standard 204 is applicable to them are as follows: Maternity Community Paediatrics
Q4 - Peter Carr (Executive Director of Therapies and Health Science) has overall responsibility for the NICE Quality Standard 204 statement.
Q5 - Non applicable, we have not created a review sheet
Q6 - The Health Board is responding to NICE Quality Standard 204: Maternity services - embed NICE guidelines into care. The Health Board have a public health midwife who leads on substance and alcohol misuse. All women are asked about alcohol at booking and during pregnancy they are signposted to healthier together with information regarding alcohol; Community Paediatrics - are developing a guideline and pathway for assessment of FASD and it will need to link with the proposed 0-18 ND pathway.
Q7 - Maternity services have a well-established service user group and service engagement forum.
Q8 – No
Comment from National FASD – This Health Board is taking action on NICE QS 204. It states it is developing a pathway and guideline for assessment of FASD and this is encouraging. The reply is silent on the cross-sector training as called for in NICE QS 204, and as such it is not possible to ensure Statements 1 and 2 are being upheld. The response is silent on whether they are using indicators in NICE QS 204 to track improvements in services.

Commissioning Response:

C1 - No, the Health Board does not commission services for the diagnosis and management of people of any age with FASD (Foetal Alcohol Spectrum Disorder).
C2 – Not applicable
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD.

Betsi Cadwaladr University Health Board

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response

Q1 - Yes via Clinical Advisory Groups – and we have ensured further recirculation
Q2 – Yes
Q3 - Paediatrics Services and Womens Services (Maternity)
Q4 – Statement 1 - Womens Services – Maternity; Statement 2 - Womens Services – Maternity; Statement 3 - Primary Care, Health visiting and school nursing services,
Children's social care services; Statement 4 - While we do not have any specific pathway for children whom have a diagnosis of FAS / FASD – we would consider referral for an ND assessment in the same way we would for any other child, taking their FAS/ FASD into consideration as part of this consideration. Our Community Paediatric Services take a lead in co-ordinating care for children and young people for which antenatal exposure to alcohol or a diagnosis of Fetal Alcohol Spectrum Disorder. We have strong links between services including clinical genetics, neurodevelopment service our child development centres and mental health services for children and young people. Care management plans are tailored to the individual needs of each child. Usually these will be co-ordinated by the community paediatric service, however, in some circumstances, e.g. if there are significant mental health needs or significant physical health needs, other services may lead care to reflect the priorities of the child or young person's health needs. Care management plans, in the form of clinic letters, are routinely shared with educational settings; Statement 5 - These children will continue to be reviewed and monitored under our community paediatric service. As part of this they will have a clinic letter, usually at least annually, which will be the overarching clinical management plan for the child.
Q5 – Included a review sheet
Q6 - NA. Please see above.
Q7 - All patients are screened at booking for alcohol consumption. Those with high consumption pre-conception will be referred to our Drug and Alcohol midwife. Those who continue to drink in pregnancy will also be referred to the Drug and Alcohol midwife.
Q8 - We give out this guidebook for all women at booking in either digital or hard copy whatever is preferred which covers general guidance (Every Child Your Pregnancy & Birth Booklet included). All Wales

Hand Held records, due to be implemented March/ April 2024 will include a section for each appointment which triggers midwife/ obstetrician to ask about alcohol consumption, which is a new element of antenatal contacts.
Comment from National FASD – The health board note that all women are asked about prenatal alcohol exposure at booking. However, NICE QS204 states that women should be asked about alcohol throughout their pregnancy and it should be recorded. The information provided does not suggest that this is happening. The booklet provided does not give the CMO guidance until page 57 of the booklet. It doesn't list the risks arising from prenatal alcohol exposure: Miscarriage, premature birth, still birth and FASD. It does not include anything about FASD. It doesn't give advice about stopping alcohol safely if drinking regularly or dependently. The section on the developing brain near the beginning would have been a good place to talk about how even low level alcohol exposure can affect the development of the brain and the rest of the central nervous system. The response does not indicate that there has been FASD training. The co-ordinated care and use of management plans are welcomed.

Commissioning Response:
Comment from National FASD: This Health Board did not respond by the statutory deadline

---

Cardiff and Vale University Health Board

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This Health Board did not respond by the statutory deadline

Commissioning Response:
C1, C2 - There is no specific service for FASD commissioned by Cardiff and Vale University Health Board.
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD.

CWM TAF MORGANNWG UNIVERSITY HEALTH BOARD

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - The maternity department are aware of this quality standard.
Q2 - New NICE guidance is disseminated to the relevant department leads for their action, implementation or further dissemination if required.
Q3 - Maternity service have recognised this is applicable to their service.
Q4 – Statement 1 - Maternity service responsibility; Statement 2 - Maternity service responsibility; Statement 3 - Child Health responsibility; Statement 4 - Child Health responsibility; Statement 5 - Child Health responsibility.
Q5 – See question 6
Q6 - Documentation within All Wales Maternity Notes (launched April 24) includes: documentation at each antenatal appointment relating to alcohol consumption rates; 36/40 review of alcohol consumption documented; At initial booking, an initial assessment of alcohol consumption, which includes an alcohol unit calculator. Health Board follows PHW Drymester programme to support no safe level of alcohol consumption in pregnancy.
Q7 - Maternity service's Patient Reported Experience Measure (PREM) – a longitudinal survey throughout pregnancy and post natal period – asks women whether their midwife has discussed alcohol consumption and whether this information and discussion was helpful.
Q8 - N/A.
Comment from National FASD – This Health Board is partially responding to NICE QS 204, with a focus on alcohol and pregnancy aspects of the QS. It has not identified training as called for in NICE QS so it is hard to know if the advice given is being done so using motivational interviewing techniques and there is no mention of written information being given to pregnant women as called for in NICE QS 204. It has failed to identify any response to Statements 3-5 of NICE QS 204.

Commissioning Response:
C1, C2 - Our health board has not commissioned services for diagnosis and management of people with FASD. However, the Neurodevelopmental Service does accept referrals for assessment for possible FASD for children/young people, when there is evidence of pre-natal alcohol intake and neurodevelopmental type difficulties evident.
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD but they state clearly that people with FASD have access to diagnosis via their

Neurodevelopmental Service. Families should make use of this statement if seeking diagnosis.

HYWEL DDA UNIVERSITY HEALTH BOARD

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - Hywel Dda University Health Board (UHB) confirms that the National Institute for Health and Care Excellence (NICE) Quality Standard 204 on Fetal Alcohol Spectrum Disorder (FASD) has been circulated to all Midwives and Obstetricians across the UHB, by email.
Q2 - The UHB confirms that the NICE Quality Standard 204 has been identified as being applicable to the Maternity and Obstetric Service; actions have been taken to implement local guideline, which is awaiting ratification.
Q3 – See above
Q4 – Statement 1 - The UHB confirms that all Midwives discuss alcohol consumption and the risks associated with FASD. Those who require further support to be alcohol free during pregnancy are referred to the UHB's Drug and Alcohol Prevention Services and specifically to the Community Drug and Alcohol Team (CDAT), who will then assess and formulate a plan of care. Additionally, due to the risks to the fetus, they will be referred for Obstetric-Led Care, where an individualised plan will be made for pregnancy and birth. This plan will encompass fetal growth monitoring, referrals to other services, such as Perinatal Mental Health Service and the UHB's Health Safeguarding Team/ Specialist Midwife, if required; Statement 2 - The UHB confirms that all women/birthing persons are asked about alcohol use prenatally in their initial weeks of pregnancy, during the initial appointment with their Midwife, which is typically undertaken around seven (7) to nine (9) weeks' gestation. Midwives record all discussion assessments, including alcohol consumption, in the All-Wales Maternity Record (a patient's hand-held notes). Women/birthing persons will have discussions with Health Care Professionals (HCP) throughout their pregnancy dependant on their circumstances, and they will be routinely asked about alcohol use in pregnancy at thirty-six (36) weeks' gestation of pregnancy. The initial assessment and the 36 weeks' gestation data is recorded on the Maternity Section of the UHB's Welsh Patient Administration System (WPAS); Statement 3 - The UHB confirms that it does not currently have a specific pathway in place for suspected FASD. However, there are generic referral pathways to Community Paediatricians for developmental delay or the Neuro-Development team (NDT) regarding a possible neuro-developmental disorder, where a multi-disciplinary plan will be made for the care of the neonate following birth; Statement 4 - The UHB confirms that those with suspected FASD are currently referred to Community Paediatricians for developmental delay assessments; Statement 5 - The UHB confirms that it does not have a specific service or expertise at present for FASD.
Q5 - The UHB does not hold this information.
Q6 - The UHB confirms that a guideline outlining care for those who are pregnant and misusing substances (including alcohol) is currently in the process of being ratified. This guideline will include NICE Guidance, recommendations regarding assessment for alcohol use using the Fast Alcohol Screening Test (FAST) tool, referral for further care and specified pathway including multi-disciplinary and multi-agency input based on the individual needs. It will also outline the expectations from those providing care to use appropriate language and a non-judgemental approach.
Q7 - The UHB confirms that there is a QR code, placed within a feedback form, which allows for anonymous feedback from all women/birthing persons receiving maternity care. This feedback is not specific to alcohol use in pregnancy, it covers all aspects of care. Additionally, an anonymous patient survey on alcohol use in pregnancy has been widely circulated on the Maternity Service's social media pages and on posters placed in all maternity specific areas across the UHB. This survey also includes feedback on knowledge of alcohol use in pregnancy and the risks of FASD.
Q8 - The UHB does not hold this information. Please see response to question 6.
Comment from National FASD: This Health Board is taking action to operationalise NICE QS 204 in terms of Statements 1 and 2. However, its response indicates that they are asking about prenatal alcohol exposure at booking and at 36 weeks but not throughout the pregnancy as called for in NICE QS 204. They clearly state they do not have a service FASD diagnosis or support, nor the expertise for it at present and there is no indication that they are providing the training as called for in NICE QS 204, nor have they indicated plans to use the indicators provided by NICE to track improvement in services over time.

Commissioning Response:
C1, C2 – "Hywel Dda University Health Board (UHB) can confirm that it does not provide any specific services for children, young people or adults with Fetal Alcohol Spectrum Disorder (FASD)."
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD.

POWYS TEACHING HEALTH BOARD

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Q1 - I can confirm Powys Maternity Services are aware of this standard.
Q2 - PTHB Maternity Services have shared this with staff who undertake risk assessments during pregnancy.
Q3 - As above, it would be applicable to Womens and Childrens Services and this has been shared within our Maternity Services.
Q4 - Womens & Children's Directorate and Primary Care Directorate are responsible for the NICE Quality Standard 204. Statement 1 - Womens & Children's Directorate and Primary Care Directorate are responsible for advice on avoiding alcohol in pregnancy; Statement 2 - This is the responsibility of Maternity Services; Statement 3 - Maternity Service, Childrens Service and Community Paediatrics are responsible for referral for assessment; Statement 4 - Community Paediatrics are responsible for Neurodevelopmental assessments; Statement 5 - Community Paediatrics are responsible for management plans.
Q5 - Please see PTHB response to question 6.
Q6 - I can confirm the documentation within All Wales Maternity Notes (launched April 24) includes: Documentation at each antenatal appointment relating to alcohol consumption rates; 36/40 review of alcohol consumption documented; At initial booking, an initial assessment of alcohol consumption,
which includes an alcohol unit calculator.
Q7 - There is no tracking specific to NICE 204. Patient experience feedback is available through the CIVICA system.
Q8 - There is no other related documentation.
Comment from National FASD – This Health Board's response indicates some action on Statements 1 and 2 which sound encouraging – particularly ensuring maternity notes now include noting of alcohol exposure throughout the pregnancy. The Health Board response, however, is silent on any action taken on Statements 3, 4, and 5 and does not outline any training or plans to track the indicators provided by NICE. It has not indicated any plans to change commissioning.

Commissioning Response:
C1a, C1b - I can confirm Powys Teaching Health Board (PTHB) Community Consultant Paediatricians provide a diagnostic service based on the Scottish Intercollegiate Guidelines Network Guide (SIGN 156 (2019)) and National Institute for Health and Care Excellence (NICE) quality standard 204. Management following diagnosis will be provided by Community Paediatric or Child and Adolescent Mental Health Services (CAMHS). Other support is provided through schools and self-help groups. Some adopted children may receive specialist services commissioned by the local authority. If any child or young person requires specialist health support not provided by Community Paediatrics or CAHMS, this would be requested from commissioned services.
C1c - I can confirm that PTHB does not hold this information. PTHB commissions services from several Welsh Health Boards and English provider organisations but does not commission services on a pathway basis. I therefore recommend that you contact the providers from whom the Health Board commissions services: The Royal Wolverhampton NHS Trust, Wye Valley NHS Trust, Robert Jones and Agnes Hunt Orthopaedic, District Hospital NHS Trust, The Walton Centre NHS Foundation Trust, University Hospital of North Midlands NHS Trust, University Hospitals Birmingham NHS Foundation Trust, University College London Hospitals NHS Foundation Trust, Aneurin Bevan University Health Board Swansea Bay University Health Board, Cardiff & Vale University Health Board, Hywel Dda University Health Board, Cwm Taf Morgannwg University Health Board
C2 - Please see response to Q1c above. The guidelines and standards are accessible online.
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD but they state clearly that people with FASD have access to diagnosis via their Community Paediatricians and care management via Community Paediatrics or CAMHS Services and some support via local authority adoption services and other commissioned services. Families should make use of this statement if seeking diagnosis.

SWANSEA BAY UNIVERSITY HEALTH BOARD

Nice Quality Standard 204 Improvements	Commissioning
	

NICE QS Response
Comment from National FASD: This Health Board did not reply by the statutory deadline.

Commissioning Response:
C1, 2 - The Health Board does not commission services for diagnosis and management of FASD (Foetal Alcohol Spectrum Disorder) in children, young people or adults.
Comment from National FASD: This Health Board has not commissioned services for services for diagnosis and management of people with FASD.

NHS TRUSTS

QUESTIONS SENT TO TRUSTS

NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder was published 16 March 2022 (https://www.nice.org.uk/guidance/qs204)
1. Please confirm, has this quality standard been circulated to each team and service in your network?

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

3. 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.

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.

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.

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

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.

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

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

NHS TRUSTS - DETAILED RESPONSES

AIREDALE NHS FOUNDATION TRUST

Response

Q1 - The QS was circulated to Obstetrics and paediatrics in April 2022 and discussed in paediatrics June 2022. The information is included in the Antenatal care of low-risk women guideline.
Q2 - Obstetrics and Paediatrics.
Q3 - Currently there is no commissioned service for assessment of children with FASD -and so no local pathways exist. Antenatal Care would comprise of referral for Consultant care and the early intervention midwife, electronic alert sent to the paediatric team. Consideration is given to referral to children's social care team and safeguarding. Support is provided to the Women via substance use service.
Q4 - No review sheet required as this is not a commissioned service.
Q5 - This is not a commissioned service.
Q6 - Antenatal education regarding alcohol use is provided and monitoring completed by the early intervention midwife along with the substance use service.
Q7 – See attached
Q8 – No
Q9 – This is not a commissioned service
Comment from National FASD: This Trust, which includes acute and community paediatric services and a child development centre clearly states it is not taking action since the services for FASD diagnosis and support are not commissioned. The response included an antenatal care guideline for maternity teams which has not been reviewed since the NICE QS and contains outdated

information about Fetal Alcohol Syndrome and is not in line with NICE QS 204 Statements 1 and 2. While it is positive that their system provides an alert to the paediatric team, there is no indication this Trust is measuring its improvement of care over time using the NICE QS 204 indicators. Nor has it indicated any FASD specific training.

ALDER HEY CHILDREN'S NHS FOUNDATION TRUST

Response

Q1 - Quality statements 1 and 2 are not applicable to our services. Quality Statements 3, 4 and 5 reviewed by Neurodevelopmental Paediatric Team.
Q2 - Neurodevelopmental Paediatric Team
Q3 - This is currently in progress.
Q4 - Please see document attached - FASD-QS204 Position Statement (February 2024).
Q5 - 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 - 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 – No
Q8 – No
Q9 - By referral to Neurodevelopmental Paediatrics.
Comment from National FASD: This Trust included a Quality Standard Position Statement that usefully lays out what the Trust's position is on each statement and then identifies actions needed. They state that Statements 1 and 2 are not applicable to their Trust. They might wish to revisit this, however, as they might still come into contact with women who are pregnant and/or planning a family and information about the risks of alcohol in pregnancy should still be available. Their position statement outlines a range of actions that demonstrate a seriousness of intent to improve their quality of services, including: coding of all children being assessed or diagnosed with FASD on trust electronic systems (to help with diagnosis rate based on population data and the numbers diagnosed), a training package for FASD for new registrars but available to the rest of the trust, a presentation regarding the SIGN and NICE guidelines in Grand Round which is hospital wide teaching (completed), communication of a dedicated service once it is completed to social care, primary care and education, participation in mapping exercises and workshops the ICB has arranged as part of the Beyond FASD steering group, liaison with ICB designated nurse and doctor for Looked After Children regarding training for FASD awareness across agencies to support better communication; a development of a management document on EPR for the possibility of bringing evidence together for FASD based on SIGN guidance, development of a business case for access to a psychologies for the neurodevelopmental team to aid the assessment process and ideally a development of a unifying streamlined service looking at all areas for FASD (currently on hold until mapping exercise is completed and resource provision is agreed), linking closely to the looked after and post adoption children, awareness of FASD via liaison with ICB Designated Doctors and Nurses for Looked After Children regarding training for outside agencies and training regarding "Care Aims" reports to improve plans for children. The plan covers most areas of Statements 3-5, though the Statement 5 plan focuses on a subset of children, those who are Children Looked After. The plan uses NICE Quality Standard 204 indicators though it is not clear how over time they intend to track continuing progress.

ASHFORD AND ST. PETER'S HOSPITALS NHS FOUNDATION TRUST

Response

AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST

Response

Q1- 9 - Avon and Wiltshire Mental Health Partnership NHS Trust provides healthcare for people with serious mental illness, learning disabilities and autism in inpatient and community-based settings. As a mental health trust we do not provide services regarding foetal alcohol spectrum disorders.
Response
Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004) Their autism and learning disability service will undoubtedly include people with FASD who according to NICE QS 204 Statements3-5 should be appropriate assessed and supported.

BARKING, HAVERING AND REDBRIDGE UNIVERSITY HOSPITALS NHS TRUST

Response

BARNET, ENFIELD AND HARINGEY MENTAL HEALTH NHS TRUST

Response

Q1-9 - We do not provide mentioned services and our systems show that the mentioned guidance is not currently listed, therefore this is not applicable.
Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with

FASD present with mental health issues (Streissguth et al., 2004) and they also could also have pregnant women using their services.

BARNSLEY HOSPITAL NHS FOUNDATION TRUST

Response

Q1 – Yes
Q2 - Community Paediatrics, Maternity, Safeguarding Team.
Q3 - a) children and young people (aged 0 to 25); Yes there is full service that cover children and YP Service; b) children and young people with special educational needs and disability; There is a LD nurse in role for the trust and will cover and support for SEND children; c) safeguarding (all-ages); Full team for BHNFT that cover children, maternity and adults areas; 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. The named nurse for children is leading onFASD and linking in with training and oversight of FASD with the local authority. This is early stages and awaiting to review how this will be incorporated into safeguarding. FASD is included in the risk assessment process when pregnant women present and disclose drinking in pregnancy.
Q4 - Please see attached. We do not consider the outcome measures as part of our process.
Q5 – N/A
Q6 - As above Q3.
Q7 - Please refer as above to Q4.
Q8 - We do not a pathway or resource for FASD. ICB has not commissioned a pathway for FASD
in Barnsley. We do not have a process or the right professionals to assess FASD.
Q9 - As above
Comment from National FASD: This Trust has taken some action to ascertain the relevance of NICE QS 204 to different teams and services. Their review sheet indicates they are in compliance with Statement 1 and states that this can be tracked electronically. They do not record alcohol use throughout the pregnancy. Their review sheet states they are seeking change to their digital system to prompt throughout pregnancy. They state they are not getting information in referrals about alcohol exposed pregnancies, that there is no commissioned service for diagnosis and not the 'right' professionals to assess, and their review sheet states there is no management plan per Statement 5, nor are they using NICE indicators to measure improvements. The response indicates there is some training across services as called for in NICE QS 204 being arranged with the local authority. It's also encouraging that they have identified the named nurse for children as the lead.

BARTS HEALTH NHS TRUST

Response

Q1 - Yes it has been circulated to the clinical teams.
Q2 - Community Paediatric services, maternity, neonatal, ED, Safeguarding.
Q3 - Neonates observe as per the NAS guidelines and assessment tool. Yes we do lead for these area (SEND for Tower Hamlets) – but we don't have evidence that the NICE FASD Quality Standard 204 has routinely been included in decision making.
Q4 - Nice lead has been allocated however the trust does not hold a review sheet.
Q5 - 6 - No information held
Q7 - 9 Observe as per the NAS guidelines and assessment tool.
Comment from National FASD – This Trust has not demonstrated it is taking action specific to the improvement in care as outlined in NICE QS 204 and states clearly they have no evidence that NICE QS 204 has been routinely included in decision making. Relying simply on a NAS guideline does not demonstrate the Trust is in line with SIGN 156 and NICE QS 204 with regards to best practice on alcohol in pregnancy. The Trust does not reference any FASD-specific training as called for in NICE QS 204 nor does it state it will track improvement of services per indicators in NICE QS 204. It is silent on how Statements 3-5 are being met by its relevant community paediatrics service.

BEDFORDSHIRE HOSPITALS NHS FOUNDATION TRUST

Response

BIRMINGHAM AND SOLIHULL MENTAL HEALTH NHS FOUNDATION TRUST

Response

Q1-9 – Please note that Birmingham and Solihull Mental Health Foundation Trust explicitly provide mental health services and do not provide physical healthcare like an Acute Trust. Your request for information is therefore not applicable to the Trust.
Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004)

BIRMINGHAM COMMUNITY HEALTHCARE NHS FOUNDATION TRUST

Response

Q1 - Yes it has been circulated to Community Paediatrics
Q2 - Health Visiting and Community Paediatrics
Q3 - Clinicians working within Community Paediatrics consider FASD as part of assessments. There is no specific commissioned service for assessment/ diagnosis
Q4 - Review sheet has not yet been completed
Q5 - Review sheet due to be reviewed and completed however as above there is no commissioned service for FASD assessment/ diagnosis
Q6 - No current involvement
Q7 – No
Q8 – No
Q9 - Children with developmental / learning delay would be referred to community paediatrics for general assessment. This would include a detailed history and may include investigations including genetic tests. Depending on history and findings children may be referred to the genetics team to rule out other conditions. Some diagnoses are given by the community paediatrician however this is challenging due to the lack of a defined pathway and the evidence required from multi-disciplinary team. Children with concerns about possible ADHD/ASD would be referred directly to the ADHD/ASD pathway. FASD may be considered as part of the presentation and assessment however it is not an assessment pathway for FASD specifically and a diagnosis would not be given during this assessment. If there are concerns which might suggest this children can then be referred to community paediatrics for assessment but these would only be seen if fulfilling the remit of our current referral criteria for Community Paediatrics and wouldn't necessarily be seen for FASD assessment specifically if there are no developmental concerns as part of this.
Comment from National FASD – This Trust is taking partial action but repeatedly refers to the lack of commissioned services. Its response indicates it is not following SIGN 156 guidelines (which is the current diagnostic guideline in England) which states, "Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile."[57] It makes no reference to its role in care management, including for adults with FASD. Nor has it indicated FASD training across services is being provided as called for in NICE QS 204.

BIRMINGHAM WOMEN'S AND CHILDREN'S NHS FOUNDATION TRUST

Response

BLACK COUNTRY HEALTHCARE NHS FOUNDATION TRUST

Response

BLACKPOOL TEACHING HOSPITALS NHS FOUNDATION TRUST

Response
Q1 - This guidance has been circulated to all age Mental Health, Learning Disability, Neuro services and Maternity & NNU services within the Trust.
Q2 - The Children and Young Persons Learning Disability Team have identified this as applicable to them due to the high likelihood of Learning Disability in children and young people with FASD. The NNU Consultant Lead has also identified that this standard is applicable to them. Its routine enquiry to ask about alcohol use by Health Visitor at Antenatal and transfer in visits and it's also discussed as part of the Baby Steps programme. Maternity services acknowledge that this is applicable to them. At antenatal booking all women are asked about their pre-pregnancy and current alcohol use as routine enquiry. This is followed up at subsequent appointments. Clear and consistent messages are given about avoiding alcohol in pregnancy and the benefits of doing this. Where there are concerns around alcohol use during pregnancy referrals are offered to specialist alcohol services.
Q3 - All clinical leads are aware of the NICE guidance and refer to it when appropriate.
Q4 – 5 - The Clinical audit & effectiveness lead send NICE guidance out to the appropriate Divisions to review and create an action plan where any changes need to occur. This NICE guidance is currently under review with the Division
Q6 - We regularly attend meeting and engage with our parent forum group.
Q7 – No
Q8 - Our Trust has not been commissioned to provide any service.
Q9 - In the Children and Young Persons Learning Disability Team a referral would be made to the team and this would be screened for a likelihood of a co-occurring learning disability.
Comment from National FASD – This Trust has distributed NICE QS 204 and states it is currently under review, but it has not yet laid out plans to improve quality of services based on NICE QS 204. It has not identified training across services as called for in NICE QS 204. For example this can ensure that maternity services are using best practices regarding alcohol in pregnancy questions, providing written material and continuing those discussions throughout pregnancy even if there was a negative answer at the booking appointment. The Trust is not yet using NICE indicators to track improvement in quality of care.

BOLTON NHS FOUNDATION TRUST

Response

[57] SIGN 156 (2019), p. 3. https://www.sign.ac.uk/media/1092/sign156.pdf

BRADFORD DISTRICT CARE NHS FOUNDATION TRUST

Response

BRADFORD TEACHING HOSPITALS NHS TRUST

Response

BRIDGEWATER COMMUNITY HEALTHCARE NHS FOUNDATION TRUST

Response

BUCKINGHAMSHIRE HEALTHCARE NHS TRUST

Response

CALDERDALE AND HUDDERSFIELD NHS FOUNDATION TRUST

Response

Q1 - We do not hold information to confirm if this was circulated.
Q2 - Maternity services/Substance misuse specialist midwife/Paediatric and neonatal services (Children and Young peoples services)
Q3 - We are unable to confirm the trust leads have considered this quality standard in implementation.
Q4 - Not applicable
Q5 - We do not presently have a review sheet, however, all patients with suspected Fetal Alcohol Syndrome in the ante natal period would be referred to a paediatrician for onward care input. The patients would then be referred onward, as appropriate, to specialist clinicians. We will undertake a review to understand the demand and ultimate capacity required and any quality improvement gaps.
Q6 - Active Paediatric user forum. Currently in process of launching parental user group
Q7 - None available
Q8 - We are unable to confirm if this has been commissioned.
Q9 - A referral to paediatric services would be made by relevant other care provider and the child / young person would be assessed in outpatient services and appropriate care pathways implemented.
Comment from National FASD: This Trust has not demonstrated it is taking any action to improve its quality of services as called for in NICE QS 204. In their response they refer only to Fetal Alcohol Syndrome, indicating that they have not taken on board SIGN 156 diagnostic guidelines which serve as the basis for NICE QS 204 and they do not indicate any staff training as called for in NICE QS 204. There is no specific information provided on how their maternity and sexual health services are meeting Statements 1 and 2, nor any information that their CAMHS or Children's and Young Peoples Services and other services such as speech and language therapy are improving their quality of care related to Statements 3-5.

CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

CAMBRIDGESHIRE AND PETERBOROUGH NHS FOUNDATION TRUST

Response

Q1 - OPAC & CYPF
Q2 - Clinical Director of Children, Young People & Families directorate.
Q3 - Clinical Director of CYPF reviewed on 3/09/2022 (due for renewal on 12/09/2024)
Q4 - shown on baseline assessment sheet/tab
Q5 - N/A
Q6 - CPFT is not commissioned to provide services and this was highlighted to the ICB commissioners.
Q7 - N/A
Q8 – No
Q9 - Not assessed as it is not commissioned. Referrals are not accepted.
Comment from National FASD – This Trust has determined Statements 3-5 are applicable to them but it has not demonstrated it is taking action. The response indicates that they are not assessing and not accepting referrals because the ICB has not commissioned services. The response is silent on the training that is called for in NICE QS 204.

CAMBRIDGESHIRE COMMUNITY SERVICES NHS TRUST

Response

Q1 - Yes QS204 (Datix id 1635) distributed 16/03/2022.
Q2 - Beds Ch 0-19 KC Quality standards template completed. 3 out of 5 statements relevant 2 fully met 1 requiring action see below; Beds CCN Jo MC & GM No response; BEDS & LUTON PEADS Circulated to team no action required; Dr TB NO Baseline assessment required. Dr TB: To be discussed in academic meetings - email sent to Bedford and Luton teams; Cambs & Norfolk Child Received- No action required (0-19); Dr JT Cambs & Norfolk Child Received- No action required (0-19); SD LUTON Adult Received No action required Added to staff messages; M McH LUTON & BEDS Therapy Received No action required Added to staff messages; HU MSK Received-no action required; JD OZC Received-no action required;

LP Jo RADNOR Alert circulated to team - no further action EB required; DENTAL Received- no action required; JHS; QSST Beds Child KC, Statement 2 & 3 statements fully met. Statement 1 : Advice on avoiding alcohol in pregnancy- Partially met. Current practice: Currently pregnant service users are asked about alcohol consumption; this is recorded on the MECC template. There is no specific area to record that risks of alcohol consumption have been discussed. Risk identified: Increased risk of Fetal alcohol syndrome. Action identified: Specific recording box to evidence discussion of risks of alcohol consumption in pregnancy to be added to antenatal template. Result: Request placed with SY1 team re-amending and adding to template and was completed see below
Q3 - This data is not available as all children leads need to be contacted and it will take an excessive amount of time to collate the data.
Q4 – 5 - The Trust have a NICE log (excel sheet) which detail who the guidance went to and response - they respond through Datix and this is then transferred to the log. See above.
Q6 – N/A
Q7 – No
Q8 – Not known
Q9 – N/A
Comment from National FASD: This Trust has circulated NICE QS 204 and has identified and actioned a need to change the electronic system to record exposed pregnancies as per Statement 2. It states it is compliant with Statements 1 and 3, and 4 and 5 are not applicable. However, in their response regarding the importance of noting AEP, they refer to Fetal Alcohol Syndrome, which is an outdated diagnostic term. They have not demonstrated that any training on FASD is underway. They are not tracking indicators provided by NICE QS 204 to measure improvements in their quality of care. The Trust's response has taken a narrow view of NICE QS 204's call for improvement of services, for example, this Trust has a full range of Children's Services, including for behaviour, emotions and mental health, speech, language and communication, occupational therapy, children in care and many more – these practitioners will all be part of recognising and care management for people with FASD as called for in Statements 3-5.

CAMDEN AND ISLINGTON NHS FOUNDATION TRUST

Response
Q1 – 9 - Having completed enquiries within the Trust, and in respect of Section 1(1)(a), Camden and Islington NHS Foundation Trust (FT) does not hold information relating to your request.
Camden and Islington NHS FT is a Mental Health Trust, providing high quality, safe and innovative care to our patients in the community, in their homes or in hospital. Due to the nature of the services that we provide we do not hold information related to your request. For information on our services please see our website.

Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004)

CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST

Response
Q1 - Yes, the NICE 204 guidance is circulated in the services that offer support in sexual health and HIV. Staff working in services are aware of the guidance and they have advice on the risk of alcohol and drug in the operating procedures of the sexual health services. Team in the services work within the framework of understanding the guidance; this is evident in the history taking, nurses during the consultation ask about the history and the complete risk assessment in this regard. Clinicians give general advice about the risk of alcohol and drug during pregnancy. The services give Easy Read guides explaining the advice given. When young women inform about drug and alcohol and drug abuse during their pregnancy the team refer to local safeguarding team responsible lead and this can be escalated to social care as the needs arises. Also circulated to our child development centres (CDC) clinicians via the clinical leads in each borough.
Q2 - CNWL Sexual Health Services: We have Sexual Health and HIV Services at the Archway Centre, 681-689 Holloway Road, N19 5SE; And Barnet Sexual health service located at Edgware Community Hospital, Lower Ground Floor, at Burnt Oak Broadway, Edgware, HA8 0AD. Standards 4 and 5 are relevant to our CDC's. We provide these services in Harrow, Hillingdon Milton Keynes and as part of NHS partnerships in Ealing and Camden.
Q3 - We have confirmed the areas of responsibility for the standards through CDC as outlined below.
a) children and young people (aged 0 to 25); b) children and young people with special educational needs and disability; SEND lead, CDC Consultant; c) safeguarding (all-ages); Named doctor for SG; d) learning disability and autism (all-ages) ASD lead – CDC Consultant. We confirm that the sexual health services and safeguarding within the service have included FASD and implementation of the NICE FASD Quality Standard 204 in their decision making about service process and assessment of local needs. In the sexual health services the Operation Consultant, in Sexual Health the Safeguarding Leads, for Archway Sexual Health Services (which accept referrals from Camden and Islington, the service accepts referrals of patients from Haringey but they need to be referred via the Archway Services) the Specialist Sexual Health Nurse; at the Bridge Service (Barnet Patients) the Specialist Learning Disability Sexual Health Nurse.
The services cover the history and assess risks. In the initial enquiry or core assessment when the service identifies risk of alcohol consumption during pregnancy

they give the relevant information and alert social care, GP and the teams of professionals around the person. Our CDC teams individually have reviewed the NICE FASD quality standard and consider them in relation to their care pathways. There has not to date been a Trust-wide mapping of service provision for assessment and diagnosis of FASD.
Q4 – Nil
Q5 - We are happy to consider improvements in measuring the outcome of the current treatment and service in place.
Q6 - We are undertaking QI work to ensure NICE Quality Standard 204 is available in an Easy Read format. CNWL's QI work has a strong emphasis on patient involvement.
Q7 - https://staff.cnwl.nhs.uk/application/files/6515/8195/7737/Safeguarding_Adults_for_Sexual_Health_Services.pdf; and https://staff.cnwl.nhs.uk/application/files/2015/8195/7667/Young_People_Policy.pdf
Q8 - We have services in Camden, Islington and Barnet.
Q9 - The Quality standard report concluded 5 quality statement: Statement 1: Pregnant women are given advice throughout pregnancy not to drink alcohol (Not CDC, this is maternity services, GPs….etc); Statement 2: Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded (Not CDC, this is maternity services, GPs….etc); Statement 3: Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment (We follow this and we refer these children to the National Centre in Surrey).; 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 (Not CDC, we refer them to a specialist centre for assessment and diagnosis of FASD); Statement 5: Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs (Not CDC as we do not provide interventions. This is for CAMHS, schools, PBS team, social care, early intervention….etc).
Comment from National FASD – This Trust is taking action. It is especially encouraging to note their efforts to provide information in easy read format. The Trust relies on referrals to the National FASD Service in Surrey however, which involves cost and delay. It raised the question as to whether this is sustainable and if waiting times increase, if they then commission more local service? The Trust notes they have not yet done mapping of service provision for assessment and diagnosis and it has not indicated any additional training across services as called for in NICE QS 204 so it is not clear if the information being provided to pregnant women meets Statements 1 and 2 (including providing written material) or if others across services have the most up to date information on how to recognise, diagnose and manage care for people with FASD as they transition into adulthood.

CENTRAL LONDON COMMUNITY HEALTHCARE NHS TRUST

Response
Q1 - The Quality Standard was circulated to Trust's the relevant teams and services.
Q2 - QS204 was circulated to the following services within CLCH: health visiting, family nurse practitioners, employee health. A compliance statement (NBAF) was requested from these services if they deemed it relevant.
Q3 - The Trust is currently commissioned to deliver the national Healthy Child Programme for children and young people aged from 0-19. The Associate Director for Safeguarding and Children's Public Health Nursing leads on a) children and young people, b) children and young people with special educational needs and c) safeguarding (all ages), with the Deputy Chief Nurse leading on learning disability and neurodiversity. The NICE Quality Standard 204 (QS) was circulated to relevant teams and services across Trust and will be included in the Trust's Antenatal Standard, which is under review. Members of the Trust's Safeguarding Service or Health Visitors attend monthly midwifery liaison meetings to share information and plan care for pregnant women identified as being vulnerable and at increased risk. This includes women who drink alcohol during their pregnancy, thereby placing their unborn baby at risk of FASD. The detrimental impact of alcohol on the developing foetus is likely to be identified in pregnancy and monitored by midwives, obstetricians and neonatologists. Once information is shared with health visitors they will undertake a targeted antenatal contact to the pregnant woman and attend midwifery and local authority meetings to assure services are in place to meet the needs of the child and mother. The Health Visitor will be part of the team around a child with FASD working with paediatricians, therapists, general practitioners, social workers and parents or carers to support the child in meeting their social, educational and health potential.
Q4 - The Trust has currently not created a review sheet but will work with Commissioners regarding service provision and delivering outcome measures.
Q5 - The Trust has working groups in place to review existing antenatal pathways, services to children with SEND and those transitioning into adult services. The working groups include Designated Clinical Officers for SEND from the Integrated Care Boards in the boroughs where the Trust delivers 0- 19/adult services.
Q6 - The Trust Patient Experience Team. Patient Advocacy and Liaison Service and frontline practitioners and managers seek feedback from stakeholders, which includes recording patient stories, which are used to promote learning and to improve the delivery of quality care.
Q7 - The Trust does not have specific guidance relating to QS 204.
Q8 - No
Q9 - A person with possible FASD would be referred by health visitor, school nurse or therapist to their general practitioner for referral to specialist paediatric service

for assessments and investigations to support a diagnosis of FASD and the development of a multiagency plan to support the individual and their parent/carer.
Comment from National FASD: This Trust is beginning to take action but has not fully responded to NICE QS 204. For example it is unclear if the staff across services have the training called for in the QS to ensure an adequate response.

CHELSEA AND WESTMINSTER HOSPITAL NHS FOUNDATION TRUST

Response
Q1 - Circulated within paediatric teams and within Maternity service
Q2 - All Maternity teams providing Antenatal care: hospital antenatal team, community midwifery teams, birth centre teams. Genetics and neurodevelopment within paediatrics
Q3 - FASD is considered in all neurodevelopmental assessments including autism and we ask in the developmental history if alcohol was consumed during pregnancy as standard. Teaching regarding NICE guidelines was given by a Consultant in Paediatric Neurodisability and the Chief Executive of the National FASD organisation to discuss the new NICE Quality Standards.
Q4 – N/A
Q5 - N/A – guidelines are already implemented within paediatrics
Q6 - Unaware Paediatrics. For Maternity, MNVPs (Maternity and Neonatal Voices Partners) are involved in the co-design and implementation of Trust responses to all NICE quality standards.
Q7 – N/A
Q8 – N/A
Q9 - They would attend an assessment through our paediatric neurodevelopment.
Comment from National FASD: This Trust is taking partial action on NICE QS 204. It is particularly encouraging to hear prenatal alcohol exposure and FASD is being considered in all neurodevelopmental assessments. The Trust however has not provided information to indicate whether or not they have conducted the multisector staff training that is called for in NICE QS 204 to ensure all staff are aware of latest diagnostic guidelines and it is hard to know if the improvements called for in NICE QS 204 are reverberating throughout their Trust. The Trust's services include A&E, audiology, cardiology, children's orthopaedics, dentistry, ear nose and throat, neonatal, neurology, speech and language, ophthalmology, and more – these would all be involved in FASD recognition and possible care management as called for in Statement 5. Their early pregnancy, fertility, maternity gynaecology, sexual health services all will need training to ensure Statements 1 and 2 are being implemented according to best practice – with routine discussions throughout pregnancy and providing written materials to pregnant women. The Trust's response does not demonstrate they are tracking the indicators provided by NICE QS 204 to ensure improvement in quality of care. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

CHESHIRE AND WIRRAL PARTNERSHIP NHS FOUNDATION TRUST

Response

CHESTERFIELD ROYAL HOSPITAL NHS FOUNDATION TRUST

Response

THE CHRISTIE NHS FOUNDATION TRUST

Response
Q1 - The Christie is a tertiary cancer specialist hospital. The guidance (Fetal alcohol spectrum disorder) was assessed at the appropriate governance committee (CREC) as not applicable to our services.
Q2 - 7 – n/a
Q8 - As a tertiary Cancer Centre that doesn't provide FASD services we are unaware of the ICB's commissioning arrangements for this service. Therefore, the Trust cites section 1(1) of the Freedom of Information Act, in declining to respond to your request, on basis we hold no data in respect to this element of your request.
Q9 – n/a
Comment from National FASD: Whilst we recognise this is a specialist trust, their staff will still need training, people with FASD get cancer and the Trust may well be part of care management as called for in NICE QS 204 Statement 5.

CLATTERBRIDGE CANCER CENTRE NHS FOUNDATION TRUST

Response
Q1-9 I can confirm that our Trust does not hold any information in this regard. Our Trust is a tertiary specialist cancer treatment centre. Therefore, the information you have requested is not applicable to our Trust in this instance.
Comment from National FASD: Whilst we recognise this is a specialist trust, their staff will still need training, people with FASD get cancer and the Trust may well be part of care management as called for in NICE QS 204 Statement 5.

CORNWALL PARTNERSHIP NHS FOUNDATION TRUST

Response

Q1 - The NICE quality standard 204 on FASD would be relevant to the Neuro- developmental Assessment Team who are commissioned to deliver neurodevelopmental assessment to include differential diagnosis for FASD. The standard is currently with the operational lead to review the guidelines alongside a paediatrician with FASD expertise. The Trust's Perinatal Lead has also been made aware of the quality standard.
Q2 - In March 2022, when the guidance was first published, Children's services deemed the quality standard was not applicable as the Trust was not commissioned for FASD, it was something that would be considered as part of the Neurodevelopmental assessment pathway, however, the guidance is now deemed more relevant and will be considered. The Trust's Perinatal Service has identified that parts of the guidance are applicable to them.
Q3 - Trust leads would expect this to be delegated to senior operational leads with Children and Young People's services to manage NICE guidance through our governance processes and would seek that assurance through internal reporting, and service planning for commissioned services would fall into local transformation/business development plans managed through delivery board and project management updates. This will be reviewed as part of the Trust's NICE review cycle by the appropriate operational lead as there is part of the guidance in our new commissioning arrangements that will now apply.
Q4 - The review of the quality standard is currently underway.
Q5 - The Children's system within Cornwall is undergoing significant transformation in its Neuro Diversity Strategy. How services are co-ordinated and delivered will define clinical pathways and offers of support within neurodevelopmental presentations will be NICE informed. There is joint approach to FASD assessment between the Trust's neurodevelopmental team and paediatrics to work on. Alcohol use is asked at every new patient assessment in Perinatal service. Advice is given as identified by the chief medical officer regards abstinence in pregnancy. Referrals made to appropriate services if alcohol use is problematic.
Q6 - There has been significant engagement with service users for the ND strategy but not FASD specific. Individual feedback from families after assessment has been very positive.
Q7 - This is currently under development.
Q8 - The ICB are commissioning the service within the new joint ND specification for the acute and community providers, but there is work to do on allocation of resources and demand and capacity planning to ensure there is a clear and funded pathway for FASD. At present assessments are being delivered (see below) on a case by case need to ensure needs are being met.
Q9 - For children who need to be assessed for FASD to differentiate from autism, the Trust carries out the assessment according to the NICE guidelines. This involves an assessment with a paediatrician who identifies: Indications of Prenatal Alcohol Exposure on the system or during parental history – the Trust requires direct admission from parent or NHS, or police report to confirm. If no direct admission but concerns, the Trust will look for the 3 facial sentinel features as laid out by the Sign 156/Nice guidance.
If the child has 3 sentinel facial features, they automatically meet the criteria for a diagnosis of FASD, however, the Trust tends to complete the assessment below to identify areas of greatest need.
A diagnosis of FASD is only made when there is evidence of maternal alcohol consumption during pregnancy, and/or three facial sentinel features, and pervasive brain dysfunction, which is defined by severe impairment in three or more of the following neurodevelopmental domains: motor skills, neuroanatomy/neurophysiology*, cognition, academic achievement, memory. attention, executive function, including impulse control and hyperactivity, affect regulation and adaptive behaviour, social skills, or social communication. In order to identify severe impairment (2 SD away from the norm) we use the WISC- V (cognition), ABAS-3 (parent report of functional skills), Brief-2 (parent report of executive functioning), Movement ABC (motor skills), ADHD diagnosis process including QB when required, Neuro exam, ADOS (social communication), Parent and school history. The Trust tries to get as comprehensive assessment as possible.
Comment from National FASD – This Trust has indicated it is currently reviewing the NICE QS as part of their neurodevelopmental assessments, which is encouraging. It has not indicated if the training called for by the NICE QS 204 is underway across services which will be needed to ensure best practice and current guidelines and to ensure prenatal alcohol exposure is being properly noted. For example, the response indicates the type of proof needed to demonstrate an alcohol-exposed pregnancy which is counter to that listed in SIGN 156, the current diagnostic guideline in effect. They also do not indicate a genetics test as called for in SIGN 156. The use of the term 'admission' in this response is not in line with best practice. It also states that a maternal alcohol history is taken on intake but not throughout the pregnancy as called for in NICE QS 204 and is silent on whether or not written information is provided to pregnant women.

COUNTESS OF CHESTER HOSPITAL NHS FOUNDATION TRUST

Response

COUNTY DURHAM AND DARLINGTON NHS FOUNDATION TRUST

Response

Q1 – Yes
Q2 – 3 - This NICE guideline is relevant to the

Community and Developmental Paediatric team and as per FASD Audit demonstrates consultants are aware of this and are using the NICE guidelines appropriately.
Q4 - Please see the attached document.
Q5 - Internal guidelines are planned to be reviewed and updated in line with NICE standards which are currently being used to assess and diagnose FASD.
Q6 - General Manager is sighted on this and will engage with commissioners.
Q7 – No
Q8 - It is under review with the ICB commissioners at this stage. Potential for plan in 24/25.
Q9 - Please see attached document.
Comment from National FASD: This Trust states on its website that it has 7,000 staff serving a population of 650,000 people. Using the low end FASD prevalence rate of 2%, some 13,000 people in their services are likely to have FASD – most will be undiagnosed but using their services and relying on the staff to help recognise, diagnose and manage their underlying brain damage, particularly as they have a Community and Neurodevelopmental service and related services including speech and language, occupational therapy and many more. They have not indicated any FASD specific training for their staff. It is encouraging to hear an FASD audit was conducted. Their response to date does not indicate any intention to use NICE indicators to monitor improvements in services. Their reply is silent on how its maternity services are responding to Statements 1 and 2. We note that their review sheet states they will not be compliant with Statement 5: "We do not have the resources in Community and Neurodevelopmental Paediatrics to make a management plan for a child's needs, unless these are related to a specific health condition such as epilepsy. We do not produce a management plan as often the child or young person's needs are related to their behaviour or education. We cannot specify how these needs should be met as we do not have expertise in mental health, behaviour or learning support. If there are no health needs identified, then we would discharge the child or young person once a diagnosis of FASD has been made or excluded."

COVENTRY AND WARWICKSHIRE PARTNERSHIP NHS TRUST

Response

CROYDON HEALTH SERVICES NHS TRUST

Response

CUMBRIA, NORTHUMBERLAND, TYNE AND WEAR NHS FOUNDATION TRUST

Response
Q1-9 - As a Mental Health and LD Trust, CNTW is not commissioned to assess/diagnose Fetal Alcohol Spectrum Disorder, as this would be undertaken by Paediatrics within an 'Acute Trust' NHS setting.
Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004)

DARTFORD AND GRAVESHAM NHS TRUST

Response
Q1 – Yes
Q2 - Maternity and Paediatric Governance Teams
Q3 – No
Q4 - No review sheet created
Q5 - The Trust is not currently responding to these.
Q6 - We currently don't have a plan for this.
Q7 – No
Q8 – No
Q9 -- The Consultant would refer the patient to Community Paediatrics and Therapists as needed.
Comment from National FASD: This Trust has failed to understand its role in prevention as well as recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204.

DERBYSHIRE COMMUNITY HEALTH SERVICES NHS FOUNDATION TRUST

Response
Q1- Yes
Q2 - Childrens 0-19 Services, General Practice, Speech and Language Therapy
Q3 - 0-19 - we have embed the evidence in terms of the delivery of the universal public health service and the implementation of the healthy child programme. GP Service – rarely see patients/families with FASD, as midwifery led, however would consult NICE guidance in the first instance and then refer to partner services.
Q4 – Review sheet provided
Q5 - N/A as have a review sheet
Q6 - 0-19 – as a universal service we do not specifically track against this standard pt experiences. GP – don't routinely track this in Primary Care
Q7 - Not applicable- no other document has been created.
Q8 – No
Q9 - 0-19 Any developmental or behavioural concerns are assessed using ASQ and referrals made into the appropriate services. Work is being undertaken at a local level to ensure pathways and guidance around this with external providers is seamless. All care is personalised to meet the individual needs of the child from the universal service.
GP – would provide a holistic method of care working with Acute, Midwifery, Drug & Alcohol & Safeguarding services.

Comment from National FASD – This Trust is taking action which is encouraging. The response does not mention and specific FASD training as called for in NICE QS 204. It is hard to imagine the response to the QS can be fully achieved in all aspects without more information on training provided. The response doesn't recognise that FASD is not 'midwifery led' and GPs are on the frontline of care for people with FASD. If there's a developmental concern the response says they are using ASQ – but as is generally focused on autism, this does not meet the range of assessments called for in NICE QS 204 statements 3 and 4. The response doesn't indicate what they are doing for older children. Are they asking about PAE? The response doesn't say anything about conducting a neurodevelopmental assessment to diagnose and is silent on what they're doing about Statements 1, 2 and 5.

DERBYSHIRE HEALTHCARE NHS FOUNDATION TRUST

Response

Q1-9 - The Trust does not hold specific information in respect of your request. The Trust can however confirm that it follows clinical guidelines around managing patients during pregnancy. Within the Trust's Drug and Alcohol services, the Service works with specialist midwives but those clinicians are not employed by the Trust.

Comment from National FASD – This Trust has not demonstrated it is taking any specific action to improve its quality of services in line with NICE QS 204. The Trust includes services that will be called upon to help with FASD recognition, diagnosis and support including: services for 'neurodevelopmental condition assessment – autism and ADHD," CAMHS, learning disabilities, occupational therapy, children in care, community paediatricians and many more. It is inconceivable that they are not regularly coming into contact with children and young people for whom Statements 3-5 is directly relevant to their care and they have not indicated if their staff have had training as called for in NICE QS 204. They have not demonstrated that their perinatal services and drug and alcohol support teams have received training as called for in NICE QS204, nor that they recognise that it is up to all healthcare professionals to help identify alcohol exposed pregnancies. It has not indicated it is taking any steps to track the indicators listed in NICE QS 204 to track improvements in services.

DEVON PARTNERSHIP NHS TRUST

Response

Q1 - Relevant teams informed

Q2 – 7, 9 - See Document

Q8 - No Information held, Devon Partnership NHS Trust is not an ICB

Devon Partnership NHS Trust is a mental health and learning disabilities Trust, please see attached document in relation to information held.

'2.3.1 QS204-FETAL ALC SPECT DISORDER CAMHS-SPECIALIST COMBINED UPDATED 230522'

From document: Low-moderate risk; need for awareness training for staff in perinatal settings and readily available health education materials within TDAS. CAMHS: Low risk due to low numbers of CYP

In TDAS, there are significant numbers of female patients who present with an alcohol problem. At assessments patients are asked if they are pregnant. A limited number of pregnant women come into contact with the service. The service would support them to safely reduce and stop their alcohol use in a timely manner and make them aware of the risks to their unborn child. TDAS would refer to safeguarding and link in with other multi-agency services to support the individual, such as midwifery and social services.

We need to ensure that health education and information is provided to these individuals about the risks of becoming pregnant whilst physically misusing alcohol.

In Perinatal services, the main gap in compliance is the need for specific training or awareness around Fetal Alcohol Syndrome.

CAMHS: Number of CYP presenting with FAS is very low – probably less than 20/year. However, there are gaps in compliance as listed below, with a number of actions identified towards achieving good compliance.

Statement 1: TDAS – this takes place; no gap in compliance. Perinatal mental health services - Not currently routine practice, unless it is discovered that patients are drinking alcohol. We could choose to issue guidance around this to state that we need to routinely advise this after women are asked about alcohol intake. Not relevant to CAMHS.

Statement 2: TDAS - this takes place; no gap in compliance. Perinatal mental health - pregnant women are routinely asked about their alcohol use. This is part of the mandatory questions as part of the initial assessment form on Carenotes. If women state that they are using alcohol then there are mandatory follow up questions to ensure that further detail around alcohol consumption is recorded and advice given. Women are reviewed regularly by midwifery staff. If Perinatal staff identify that a women is drinking in pregnancy we liaise with specialist midwives and sign post women to relevant information and support agencies. Not relevant to CAMHS.

Statement 3: TDAS - Statement not relevant for Adult Drug and Alcohol Services. Perinatal mental health - When unborn babies are identified at risk of this would be referred to the Specialist Midwife. When there are concerns about a baby's development, there are discussions with the Health Visitor with further onward referral when appropriate. Not directly relevant to CAMHS. Very rarely, CAMHS may refer to Paediatrics.

Statement 4: TDAS - Statement not relevant for Adult Drug and Alcohol Services. Perinatal mental health – Statement not relevant. CAMHS: Partially compliant. Practitioners are trained and competent to work with CYP, but most clinicians would not have had specific training in providing assessment for FASD.

Statement 5: TDAS - Statement not relevant for Adult Drug and Alcohol Services. Perinatal mental health – no

current offer to staff around FASD. Action to explore options for a suitable module. CAMHS: Not compliant. As above, no additional/ specific training in managing FASD. CAMHS unlikely to be the sole provider for the management of FASD, and more likely to manage co-morbid mental health problems.
Gap in commissioned service: There is no current training offered around Fetal Alcohol Syndrome to perinatal staff. CAMHS: There is currently no multi-agency, multi-disciplinary team providing a service for children with FASD in the county. There is no framework currently in the county for CYP under CAMHS to access.
Mandatory action: Training module to be found around Fetal Alcohol Syndrome; Resources to be made available to pregnant women attending TDAS; Training / CPD in assessment and management of FASD for CAMHS practitioners, particularly for clinicians working within Neurodiversity pathway
Comment from National FASD - This Trust has taken some action and has identified the need for training and more resources to be made available to pregnant women (this should include written information according the NICE QS 204). Their response does not indicate these conversations happen at each appointment if the woman had not mentioned alcohol use at booking. Without the training advised by NICE QS 204, it is unlikely that these conversations are fully compliant with NICE QS 204. The response refers only to "Fetal Alcohol Syndrome" which indicates the Trust is not up to date with SIGN 156, the current diagnostic guideline in England which has moved away from that term. The lack of a framework for assessment or service for FASD is a huge gap. The fact the numbers are low at the moment will be due to the lack of awareness.

DONCASTER AND BASSETLAW TEACHING HOSPITALS NHS FOUNDATION TRUST

Response

DORSET COUNTY HOSPITAL NHS FOUNDATION TRUST

Response

DORSET HEALTHCARE UNIVERSITY NHS FOUNDATION TRUST

Response
Q1 - The Quality Standard was distributed to Trust Clinical Effectiveness Group members on 5 April 2022. This multi-disciplinary multi-service group has the responsibility of reviewing guidance for relevance.
Q2 - None of the teams felt this QS was applicable to them.
Q3 - No, not deemed to be applicable.
Q4 - Not applicable.
Q5 - Quality Standards are seen by the Trust as useful tools for a service area to look at when considering a quality improvement project as recommended by NICE.
Q6 - Not applicable.
Q7 - Not applicable.
Q8 - Not as far as we are aware.
Q9 - This was deemed not applicable for a Community and Mental Health Trust.
Comment from National FASD. According to its website, "Dorset HealthCare is responsible for all mental health services and many physical health services in Dorset, delivering both hospital and community-based care. We are the biggest provider of healthcare in Dorset, and our services continually evolve and develop to meet the needs of the local community." Their services include, among other things, "district nurses, health visitors, school nursing, … sexual health promotion, safeguarding children, … audiology, speech and language therapy, … orthopaedic services" – all of these specialities will be regularly involved in improvement of services related to NICE QS 204 as well as related care management. Some 90% of people with FASD have mental health issues (Streissguth et al., 2004).

DUDLEY GROUP NHS FOUNDATION TRUST

Response

DUDLEY INTEGRATED HEALTH AND CARE NHS TRUST

Response
Q1 - Dudley Integrated Health and Social Care do not commission maternity services, therefore we are unable to complete this request.
Q2 – 9 See above
Comment from National FASD – This Trust, which is responsible for "integrating primary care across Dudley with community physical and mental health services…[and has] responsibility for the health and wellbeing of the whole population of Dudley" has failed to address NICE Quality Standard 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004)

EAST AND NORTH HERTFORDSHIRE NHS TRUST

Response

EAST CHESHIRE NHS TRUST

Response

EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST

Response

EAST LANCASHIRE HOSPITALS NHS TRUST

Response

EAST LONDON NHS FOUNDATION TRUST

Response

EAST MIDLANDS AMBULANCE SERVICE NHS TRUST

Response

Q1-9 - The ambulance service does not need to do anything as a result of these NICE guideline as it does not relate to urgent or emergency care.

Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

EAST OF ENGLAND AMBULANCE SERVICE NHS TRUST

Response

Q1-9 - we are unfortunately unable to respond to your request as we are an Ambulance Trust rather than a Hospital Trust.

Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

EAST SUFFOLK AND NORTH ESSEX NHS FOUNDATION TRUST

Response

EAST SUSSEX HEALTHCARE NHS TRUST

Response

EPSOM AND ST HELIER UNIVERSITY HOSPITALS NHS TRUST

Response

ESSEX PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST

Response

FRIMLEY HEALTH NHS FOUNDATION TRUST

Response

GATESHEAD HEALTH NHS FOUNDATION TRUST

Response

GEORGE ELIOT HOSPITAL NHS TRUST

Response

Q1-9 - Our Trust does not treat this condition.

Comment from National FASD – This Trust includes a major hospital whose services range from maternity to paediatrics to occupational therapy, speech and language therapy and many more. It has completely missed the point of NICE QS 204 – which is to establish quantifiable measures to help Trusts and Commissioners begin to track the improvement of services to help prevent damage to the brain and body by alcohol exposed pregnancies (certainly a role of their maternity and sexual health services) and to ensure those who have FASD are recognised and receive managed care – and their services have a role in this.

GLOUCESTERSHIRE HEALTH AND CARE NHS FOUNDATION TRUST

Response

GLOUCESTERSHIRE HOSPITALS NHS FOUNDATION TRUST

Response

GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

Response

GREAT WESTERN HOSPITALS NHS FOUNDATION TRUST

Response

Q1 - Yes, this has been shared with the team that undertakes the assessments.
Q2 - The community paediatric team and wider neurodevelopmental multidisciplinary team (MDT).
Q3 - The Trust has a fully integrated Neurodevelopmental Pathway for children with all neurodevelopmental and neurodisability conditions, as such The Trust were able to undertake FASD assessments as part of that pathway, which the Trust were doing before the NICE guidance was published. We have a fully integrated Neurodevelopmental Pathway for children with all neurodevelopmental and neurodisability conditions, as such we were able to undertake FASD assessments as part of that pathway, which we were doing before the NICE guidance was published.
Q4 – No response
Q5 - The Trust have implemented and audited the guidance areas that apply to our service.
Q6 - Not specifically, as indicated the Trust were already providing a service to assess CYP with possible FASD as the Trust had trained staff within our service.
Q7 - N/A
Q8 - No, there was no pathway commissioned and no funding provided specifically to this group.
Q9 - A referral is made to the Trusts Neurodevelopmental Pathway single point of access. The referral is triaged and if accepted the referral is reviewed by a consultant to decide urgency and which information needs to be gathered prior to being seen. The patient is seen by a consultant community paediatrician, who reviews the history, undertakes a physical examination, including assessment of sentinel facial features. They consider all brain domains and looks to the documents gathered to see how many have been evaluated by other professionals. Typically the consultant will assess for ADHD and executive functioning and arrange genetic testing. Other test may be ordered depending on findings, such as a brain scan. The case is taken to the Trusts neurodevelopmental MDT to explore with SALT, educational psychology and mental health services which other assessments are needed to complete the evaluation. These are organised. Once complete the assessments are sent to the paediatrician who pulls all of the information together and confirms the diagnosis. A plan for management will be decided at that time. These assessments are typically the most time intensive of all assessments carried out.
Comment from National FASD – This Trust's reply indicates it is taking some action on NICE QS 204 that sounds encouraging, though their reply does not address how the maternity services are addressing Statements 1 and 2. It is not clear from the response if other training throughout the Trust (beyond the diagnostic team) has been undertaken as called for in NICE QS 204.

GREATER MANCHESTER MENTAL HEALTH NHS FOUNDATION TRUST

Response

GUY'S & ST THOMAS' NHS FOUNDATION TRUST

Response

HAMPSHIRE HOSPITALS NHS FOUNDATION TRUST

Response

Q1 - Yes.
Q2 - The Trust's Child Health team have written a guideline in response to the quality statement 204. The Maternity service have identified that the NICE Quality Standard 204 is applicable and antenatal assessments and advice are in line with the Standard.
Q3 - Please see attached guideline document for Child Health.
Q4 - The Trust does not have a template for this standard, however this is currently under review.
Q5 - Digital maternity records monitor alcohol intake throughout pregnancy as a mandatory field.
Q6 - These are reviewed by incident forms.
Q7 - Please see attachment in question 3.
Q8 - Yes, this has very recently been approved allowing the Trust to order some specialist assessments to enable us to complete FASD assessments alongside the paediatricians. This will enable the Trust to undertake specific assessments of attention and memory, alongside our standard IQ tests. The Trust's child health referral criteria include suspected FASD.
Q9 - Please see medical assessment guide (page 4) within the policy attached in question 3.
Comment from National FASD – This Trust appears to be taking encouraging action on NICE QS 204, including ensuring this is included in maternity records. They have put in place a guideline document for assessment which also is encouraging. The response did not indicate what steps are being taken to ensure training as called for in NICE QS 204 to ensure system-wide awareness.

HARROGATE AND DISTRICT NHS FOUNDATION TRUST

Response

HEREFORDSHIRE AND WORCESTERSHIRE HEALTH AND CARE NHS TRUST

Response

Q1 - The Quality standards were published in March 2022 The information was discussed at the NICE operational group the following month. Quality Standards are normally shared for information and was on this occasion with children services

Q2 - These quality standards are applicable to our CAMHS team, our community paediatrics and therapies teams and our starting well teams. All of these teams are aware of these quality standards and the need to be vigilant to children presenting with features of foetal alcohol syndrome disorder.
Q3 - We hold no records of actions that were taken as a result of the standards publication. We are not directly commissioned to provide an assessment or management pathway for these children, however, the holistic nature of the way in which we conduct neurodevelopmental assessments for example will bring to the fore children for whom FASD is an appropriate diagnosis.
Q4 - We have not produced a review sheet.
Q5 - The quality standards will be circulated once again via our clinical governance meetings to ensure that all relevant teams within our service delivery unit are aware of them and hold them in mind in relation to service redesign and improvement.
Q6 - Herefordshire & Worcestershire Health & Care NHS trust are not currently involving stakeholders or tracking patient experiences in response to NICE Quality Standard 204
Q7 - Herefordshire & Worcestershire Health & Care NHS trust has not created any other documents related to improvement of quality of care regarding NICE Quality Standard 204
Q8 - Your request states that you require information from the ICB. Herefordshire and Worcestershire Health and Care NHS Trust is not an ICB, we are an NHS Trust providing Community and Mental Health Services in Worcestershire. Your request for information held by the NHS Herefordshire and Worcestershire Integrated Care Board and should be directed to the following address: Email: MLCSU.FOITeam@nhs.net; Click the link below for the relevant web site details: https://herefordshireandworcestershire.icb.nhs.uk/
Q9 - There is no specific FASD pathway to date within our Trust. Children and young people may still be diagnosed with the condition, but it will come to light whilst they are undergoing other assessment and treatments, for example during our thorough assessments for neurodiversity.
Comment from National FASD – This Trust has stated clearly in its reply it is not taking action on NICE QS 204 and that there is no pathway in their Trust for diagnosis. It states FASD may be recognised as part of assessments for neurodiversity but has not demonstrated that the staff has had any FASD training to ensure the latest guidelines and best practice are being followed.

HERTFORDSHIRE COMMUNITY NHS TRUST

Response

HERTFORDSHIRE PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST

Response
Q1-9 -Thank you for your request concerning Fetal Alcohol Spectrum Disorder. Hertfordshire Partnership University NHS Foundation Trust is a provider of mental health and specialist learning disability services; we feel this request is better suited to the Acute Trusts. You may wish to contact our local NHS Trusts who provide acute healthcare. I have given their details below: West Hertfordshire Hospitals; NHS East and North Hertfordshire Hospital NHS Trust; Trust Offices Lister Hospital; Watford General Hospital Coreys Mill Lane; Vicarage Road Stevenage, Watford Hertfordshire; Hertfordshire SG1 4AB WD18 0HB
Comment from National FASD: This Trust states on its website that it "supports people with mental ill health, learning disabilities and autism across Hertfordshire, Buckinghamshire, Norfolk and Waveney and Essex We employ around 4,000 people who deliver these services within the community and in inpatient settings. We also deliver a range of nationally commissioned specialist services including Tier 4 services for children and young people, perinatal services and medium and low secure learning disabilities services." This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. With its focus on specialist learning disability services it undoubtedly has people with FASD under its care and with its focus on mental health, it is not acknowledging its role in supporting people with FASD who have mental health challenges - more than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004)

THE HILLINGDON HOSPITALS NHS FOUNDATION TRUST

Response

HOMERTON UNIVERSITY HOSPITAL NHS FOUNDATION TRUST

Response

HOUNSLOW & RICHMOND COMMUNITY HEALTHCARE NHS TRUST

Response
Q1-9 - We are unable to provide you with the information you have requested under section1 (1)(a) of the Freedom of Information Act as we do not hold the information you have requested. Hounslow & Richmond Community Healthcare NHS Trust is a community Trust as opposed to an Acute Trust.
Comment from National FASD: This Trust has failed to understand its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204.

HULL UNIVERSITY TEACHING HOSPITALS NHS TRUST

Response

HUMBER TEACHING NHS FOUNDATION TRUST

Response

IMPERIAL COLLEGE HEALTHCARE NHS TRUST

Response

ISLE OF WIGHT NHS TRUST

Response

Q1 – Yes

Q2 - As per the Trusts governance process for NICE Guidance the Clinical Effectiveness Team in consultation with the applicable Clinical Specialities/ Services will review and consider all relevant guidance to determine applicability for the services provided by the organisation.

Q3 – a) We do care for children and young people, but 0-18yrs. At 18yrs they transfer to adult services; b) Response - we do care for children and young people with special educational needs as part of the paediatric service; c) The Trust works very closely with the Isle of Wight Council for all safeguarding. We also have a Children's Safeguarding team who lead on safeguarding from a health perspective; d) We do not have a separate team for Autism and Learning Disability for Children. Treatment for children 0-18yrs with FASD falls under the paediatric team as previously mentioned.

Q4 - Please see separate Baseline Assessment

Q5 - Please see separate Baseline Assessment

Q6 - The Trust does not do this specifically for this standard, but seek patient experiences regularly during any child's health journey. We also have a Youth Forum who provide stakeholder opinion for us.

Q7 – No

Q8 - From a paediatric perspective, there is no specific pathway in place for FASD diagnosis. The diagnosis cannot be made if there is no documented evidence in the maternal records, which has already been covered. If suspected FASD the child would be followed up by a paediatrician as any other child with suspected neuro-developmental delay.

Q9 - This is done in line with the PIER guidance for FASD which are shared guidelines used across the South Central area.

Comment from National FASD: This Trust has identified an action to work with the digital records team to ensure alcohol use questions are prompted to be asked throughout pregnancy, and this is positive. It claims to be in full compliance on Statements 1, 3, 4 and 5 but it does not indicate that staff across services have had FASD specific training as called for in NICE QS 204. It does not indicate any steps are being taken to track the indicators provided by NICE to ensure improvement in quality of care. The Trust's website says it is "integrated acute, community, mental health and ambulance health care provider." As such its full range of services will be called upon to support FASD recognition, diagnosis and care management and will need training for this. As NICE QS 204 states, services providers should "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."

JAMES PAGET UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

KENT AND MEDWAY NHS AND SOCIAL CARE PARTNERSHIP TRUST

Response

KENT COMMUNITY HEALTH NHS FOUNDATION TRUST

Response

Q1 - Yes. The quality standard was also circulated to members of the NICE telecon and confirmed that the Educational Lead for East Kent Health Visiting Service was the best person to review this quality standard for the organisation. The NICE telecon is comprised of representatives from all the teams and divisions across the Trust.

Q2 - The Educational Lead for East Kent Health Visiting Service was nominated at the April 2022 NICE telecon to review this quality standard for the organisation. The review sheet is attached for information.

Q3 - It has been considered as part of the overarching Community Paediatric Service. Training has been provided for clinicians and there is a Kent-wide approach to the pathway as part of the Trust's community paediatric service. The Trust also has a dedicated safeguarding service that promotes and follows the local multiagency Kent and Medway Safeguarding Children Procedures. This links to pre-birth procedures which state when a referral into social care should be completed "there is knowledge that parental risk factors e.g. domestic abuse, mental health illness or substance misuse may impact on the unborn child's safety or development". See 2.2.19 of the Parental Substance (Drugs and Alcohol) Misuse (including pregnancy which is available online at https://www.proceduresonline.com/kentandmedway/chapters/p_parent_sub_misuse.html Kent and Medway Safeguarding Children Pre-Birth procedures outline about Babies displaying Withdrawal Symptoms/Foetal Alcohol Symptoms/Signs . Information is available online at https://www.proceduresonline.com/kentandmedway/pdfs/kent_medway_prebirth_procedure.pdf?z

oom_highlight=Pre+birth+procedures#search=%22Pre%20birth%20procedures%22 For older children we would follow the Kent support level guidance which is available online at https://www.kscmp.org.uk/guidance/kent-support-levels-guidance and states for level 3; “There is a serious delay in me achieving my developmental milestones creating significant concerns.” We would also recommend a referral to the paediatrician for assessment with any developmental difficulty. The quality standards correspond with what the safeguarding team would ensure is in place as part of the plan for the child/unborn.
Q4 - This is attached. It is Trust policy to not release names and contact details of staff below Executive Director Level as this constitutes personal information which is exempt under Section 40(2) in conjunction with Section 40(3A)(a) of the Freedom of Information Act 2000 which relates to ‘Personal Information’; therefore we have redacted the names of staff from this document.
Q5 - Not applicable
Q6 - Providers in Kent and Medway have discussed processes for children and ensured local processes are the same. Patient feedback is gained after all clinical appointments for consideration where improvements can be made.
Q7 - As stated at question 4 we have created a review sheet, which is attached.
Q8 - Kent Community Health NHS Foundation Trust does not hold this information. Kent Community Health NHS Foundation Trust has not been commissioned to provide this pathway. Please redirect this part of your request to the Kent and Medway ICB.
Q9 - For community paediatrics and children’s therapies services children would be referred in regarding concerns for their development or as part of an assessment for Looked after Children/adoption procedures. A full holistic assessment would be completed along with a developmental assessment and dependent on history and clinical findings, FASD may be considered and further investigations/ assessments completed. Clinicians can request a clinical discussion with the FASD lead at Surrey and Borders Partnership NHS Foundation Trust. From a speech and language perspective the assessments that could identify FASD are the same we would use for Developmental Language Disorder (DLD) and Language and Communication Needs (LCN). Differential diagnosis with these and ASC can be very complicated and often involve multidisciplinary discussion e.g. with paediatricians. With FASD one of the essential considerations would be the detailed case history which would ask regarding alcohol consumption pre-during and post pregnancy. Within Children's Therapies we have had a small cohort of clinicians (Speech & Language Therapists, Occupational Therapists ad Physiotherapists) access FASD training and have points of contact for the team to share knowledge and skills, resources, signpost clinicians etc.
Comment from National FASD: This Trust has identified actions to help improve quality of care as called for in NICE QS 204, though not for Statements 1 and 2 which will be relevant for their sexual health services. They have flagged in their review sheet that they are non-compliant with Statements 1, 3, and 4 and they record Statement 5 as not applicable. They refer to training which is encouraging. They do not appear to be tracking the improvements by using indicators provided in NICE QS 204.

KETTERING GENERAL HOSPITAL NHS FOUNDATION TRUST

Response

KINGS COLLEGE HOSPITAL NHS FOUNDATION TRUST

Response

KINGSTON HOSPITAL NHS FOUNDATION TRUST

Response

LANCASHIRE & SOUTH CUMBRIA NHS FOUNDATION TRUST

Response

LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST

Response
Q1 – Yes
Q2 - Obstetrics and Community Neurodevelopmental Paediatrics, Neonatology and General Paediatrics.
Q3 - a) No; b) No, the FASD and NICE FASD Quality Standard 204 has not been considered in relation to SEND. SEND covers children and young people with a large range of clinical presentations and diagnosis, however the diagnosis is not focused upon - instead, items such as the EHCP, reasonable adjustments, local offer and transitions for everyone are key; c) No, the FASD Quality Standard has not specifically been considered in relation to safeguarding. If a parent/carer or parent-to-be attends the hospital e.g. A&E, under the influence of alcohol or there are concerns in relation to alcohol use, our safeguarding procedures would be followed in terms of referral to Children's Social Care in order to safeguard the child or unborn and provide further support to the parent or carer; d) No, the cause of the learning disability is not a focus area. The individual patient journey, reasonable adjustments and reducing health inequalities are a focus for the Trust.
Q4 - Obstetrics compliance assessment completed in AMaT (Audit Management and Tracking system) - attached, Community Paediatrics assessment again completed in AMaT- attached
Q5 – N/A
Q6 - Views of Parents/Carers and CYP where possible

are sought routinely in Feedback for clinical services. Trends, such as comments specifically relating to this Quality Standard, can be identified. Audits of clinical practice and service improvements can then be targeted accordingly
Q7 – N/A
Q8 - The Trust is not aware of an ICB commissioned Pathway for FASD. FASD has been discussed within the ICB Neurodevelopmental (ND) Pathway work but the focus of that work at present is on ASD services.
Q9 - Please see attached word document - 'Comm Paed report on foetal alcohol syndrome.' The community paediatric team accepts referrals for developmental delay/Autism Spectrum Disorder/ Attention Deficit Hyperactive disorder/genetic and other long term conditions. All children referred to the service are triaged. If accepted, they are assessed by a member of Community Paediatric Team. As part of assessment most of the pre-school children get developmental delay blood test screening which also involves tests to detect any genetic mistakes. Only few school-age children get blood tests particularly those with facial dysmorphism. The genetic blood tests (microarray) might rule out any possible underlying genetic conditions, but it is not 100% sensitive. Children with FASD might not have any facial dysmorphism. Children with FAS will have facial dysmorphisms. FASD is a clinical diagnosis, blood tests will not show any abnormality. Children with FASD will possibly have learning disabilities, developmental delay, might have autism spectrum disorder, might have ADHD and other difficulties. There should be a history of maternal alcohol intake in pregnancy which sometimes can be difficult to obtain as a lot of these children are 'in care' and 'looked after'. If the Paediatrician has clinical suspicion of FASD, these children are usually referred to the Genetics Team at Royal Manchester Children's Hospital for a definitive diagnosis. FASD is a multidisciplinary diagnosis, and the management is also multidisciplinary. LTHTR Community Paediatric Team does not have commissioned multi-disciplinary pathway for diagnosis of FASD.
Comment from National FASD – This Trust states in their response that they are using an audit management and tracking system to assess compliance with the NICE QS and they indicate that this AMaT system indicates 'full compliance.' However, their response does not indicate for Statements 1 and 2 any specific FASD training for maternity teams and healthcare professionals as called for in NICE QS 204 and is silent on whether or not they are providing written materials to pregnant women. They do indicate they are adding pre- and post-pregnancy alcohol questions into Badgernet and this is encouraging, so long as the questions and interview techniques are reflective of best practice for these discussions. They have not indicated how they are tracking improvements in services based on the indicators in the NICE QS. Regarding Statement 5 the Trust says it's in full compliance, saying a "'Needs based plan' is in place. There is absolutely no risk to children and families and they are well managed." However the Trust does not provide "Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations" or "Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services." Nor does it plan to track the "Proportion of children and young people diagnosed with FASD who have a management plan." In fact, they state clearly they do not diagnose FASD and they provide no FASD-specific care management and that while FASD was discussed in the ND development, there is no action identified as the pathway is focused on ASD. It must be pointed out, that their "Community paediatrics management document that is meant to show compliance is titled "Management of Foetal Alcohol Syndrome by the Community Paediatric Team" – which does not reflect current diagnostic guidance or NICE QS 204.

LEEDS COMMUNITY HEALTHCARE NHS TRUST

Response

LEEDS TEACHING HOSPITALS NHS TRUST

Response
Q1 - The standard has been circulated within the Trust.
Q2 - Standards 1 & 2 are applicable to Women's Services CSU. Standards 3, 4 and 5 are not relevant to the Trust.
Q3 - Not applicable
Q4 - Attached within appendix one.
Q5 - N/A
Q6 - Through patient experience processes.
Q7 - N/A
Q8 - Pathway would sit with Community Health.
Q9 - Asked and documented at booking. If they were using alcohol at booking then we would refer to Leeds addiction midwife.
Comment from National FASD: This Trust states it is "one of the largest and busiest acute hospital trusts in the UK." Its services include a children's hospital, children's neurosciences, occupational therapy, speech and language therapy, physiotherapy, autism services, ear, nose and throat, endocrinology, genetics, learning disabilty and much more. They state that NICE QS 204 Statements 3, 4 and 5 "are not relevant" to them despite the fact that there will undoubtedly be people with FASD accessing their services and their practitioners will often be called upon to help recognise, assess, and be involved in care management of those with FASD. This Trust states it is in compliance with Statements 1 and 2. Their review sheet says, "Full Compliance - Asked and documented at booking. We do not ask at every appointment about alcohol unless we are aware or suspicious of alcohol use. If they were using alcohol at booking then we would refer to Leeds addiction midwife." This does not reflect the best practice called for in NICE QS 204. The reply does not indicate the Trust is taking any further action to improve quality of services a called for in NICE QS 204.

LEICESTERSHIRE PARTNERSHIP NHS

Response

Q1 – 9 - Unfortunately, we do not currently hold this information. We can advise that this quality standard is being reviewed within the Trust, including networking with other Trusts, and attending teaching events on this subject. Following this, we will be looking into the development of a pathway in the community more closely.

Comment from National FASD – While this Trust did not provide any detailed response, we are encouraged that they state they are reviewing NICE QS 204, networking about it, and doing some training with an eye toward developing a pathway.

LEWISHAM AND GREENWICH NHS TRUST

Response

LINCOLNSHIRE COMMUNITY HEALTH SERVICES NHS TRUST

Response

Q1-9 - Further to the below I can confirm that the Trust will not hold the information sought as the Trust does not provide any paediatric diagnostic or maternity services. United Lincolnshire Hospitals NHS Trust may be able to assist you further.

Comment from National FASD: This Trust is not taking action. It has failed to recognise the Trust's role in Statement 5 – managing care for those with FASD and has not indicated any staff training is in place as called for in NICE QS 204 to ensure cross-service recognition of and lifelong support for those with FASD. For example, this Trust has children's services that include occupational therapy, speech and language therapy, physiotherapy – all of which can contribute to FASD diagnosis and support per SIGN 156, the current guideline.

LINCOLNSHIRE PARTNERSHIP NHS FOUNDATION TRUST

Response

Q1 – This has been shared for information with the relevant division

Q2 – This is relevant to our CYP team for information only

Q3 – We do not have a commissioned service for FASD in CYP. However, all young people that are assessed in CAMHS do have a developmental assessment as part of their initial assessment and there is a formulation clinic following that assessment. This is a multi-disciplinary clinic meeting and if FASD is identified as a potential concern then the young person would be referred to community paediatrics.

Q4 - N/A

Q5 – This has been shared for information with the relevant service

Q6 – N/A

Q7 – N/A

Q8 – N/A

Q9 – They would be referred to community paediatrics (this service is not provided by our Trust)

Comment from National FASD – This Trust provides services that include CAMHS, autism and learning disability services across the lifespan, criminal justice liaison services, a community forensic services team, neurology, speech and language therapy, perinatal mental health services and more – all of which would mean that people with diagnosed and undiagnosed FASD are likely accessing their services and their staff will be involved in care management as called for in Statement 5. The Trust has not indicated any training as called for by NICE QS 204 and has not indicated any training for or improvement in services from their perinatal teams as called for in Statements 1 and 2.

LIVERPOOL HEART AND CHEST HOSPITAL NHS FOUNDATION TRUST

Response

Q1-9 - In response to your request, we write to advise that the request is not applicable to Liverpool Heart and Chest Hospital (LHCH), and we do not hold the requested information. Liverpool Heart and Chest Hospital is a specialist adult cardiothoracic centre and does not provide treatment for Fetal Alcohol Spectrum Disorder.

Comment from National FASD – This Trust has not demonstrated it is taking action on NICE QS 204. Whilst we recognise the specialist nature of this Trust, it has failed to recognise that people with FASD often have cardiothoracic challenges as a result of their prenatal alcohol exposure and may be involved in Statement 5 care management. It has not indicated that its staff are having the training as called for in NICE QS 204. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

LIVERPOOL UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

Q1-9 - N/A, please see statement below. Section 1 of the Freedom of Information Act 2000 (FOIA) – establish if information held. Please be advised that Liverpool University Hospitals NHS Foundation Trust is an adult acute hospital and is not commissioned to provide obstetric, maternity, ante-natal, paediatric and Fetal Alcohol Spectrum Disorder (FASD) services. Under Section 1a of the FOIA, we can confirm we do not hold the information required to answer this request. Section 16 of the FOIA – duty to provide advice and assistance. In accordance with Section 16 of the FOIA, the Trust has

a duty to provide advice and assistance. On this occasion may we advise contacting the Liverpool Women's NHS Foundation Trust or Alder Hey Children's NHS Foundation Trust who provide these services for our area, their Freedom of Information Teams can be contacted via: FOI@lwh.nhs.uk; FOIRequests@alderhey.nhs.uk
Comment from National FASD – This Trust has determined NICE QS 204 is not applicable to them, despite the fact, for example, that they have an alcohol service and may well encounter pregnant women and they run an adult autism and learning disability service where they will undoubtedly come across people with FASD. They have not indicated they are taking any steps to explore best practice and their role in care management for people with FASD as they transition into adulthood as called for in Statement 5.

LIVERPOOL WOMEN'S NHS FOUNDATION TRUST

Response

LONDON AMBULANCE SERVICE NHS TRUST

Response
Q1 - 9 - We do not hold the information requested. Please note that the London Ambulance Service NHS Trust (LAS) is an emergency ambulance care service provider. Our main role is to respond to emergency 999 calls, getting medical help to patients who have serious or life-threatening injuries or illnesses as quickly as possible. The Trust does not provide specific service for Fetal Alcohol Spectrum Disorder (FASD).
Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence. We note this ambulance service provides easy read info for people with learning disabilities and autism – this should be changed to include all neurodevelopmental disabilities, including FASD. https://www.londonambulance.nhs.uk/calling-us/learning-disabilities-and-autism-zone/

LONDON NORTH WEST UNIVERSITY HEALTHCARE NHS TRUST

Response

MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST

Response

MANCHESTER UNIVERSITY NHS FOUNDATION TRUST

Response

MEDWAY NHS FOUNDATION TRUST

Response

MERSEY AND WEST LANCASHIRE TEACHING HOSPITALS NHS TRUST

Response

MERSEY CARE NHS FOUNDATION TRUST

Response
Q1 – Yes
Q2 - Children and Young People's Mental Healthcare (CYP) (0-25); Specialist Perinatal and Maternal Health Services (SPMMHS); Child and Adolescent Mental Health Service (CAMHS); Neurodevelopmental Pathway; Autistic Spectrum Condition (ASC) Adult Service; Walk-in-Centres - this forms part of the health promotion, however questions around alcohol and smoking are embedded in the standard template and, therefore, would form part of their standard practice.
Q3 - Safeguarding leads have not considered implementation of NICE FASD quality standards as they do not lead on service provision and assessment of local need. If they had a safeguarding concern that required consideration of FASD, they would look at the guidelines and make recommendations for practice if there was a concern that standards had fallen outside of the guidelines and had directly or indirectly contributed to harm. CYP 0-5 adhere to quality statements 1 and 2 at the antenatal visit and then the subsequent mandated contact. Evidence of this is embedded within each of the templates for each contact. In relation to statement 3, during mandated assessments of CYP any indicators requiring referral to community paediatricians are completed. SPMMHS explore this through the initial consultation with a woman or birthing person and thereafter during review of risk, templates available if required. ASC Adult Service: During Autism Assessment, if any difficulties with drugs and alcohol are identified with a pregnant person, further questions are asked regarding consumption and the patient is informed of awareness of dangers/possible safeguard referral.
Q4 - Please see Appendix 1 attached.

Q5 – Not applicable
Q6 - CYP&F utilise the trust patient safety and quality assurance team to support learning and improvement across services. Complaints and compliments are raised through Patient Advise Liaison Services (PALS) and the services use Friends and Family Tests (FFT) to collate feedback from patients and their families.
Q7 – No
Q8 – No
Q9 - Within CYP&F the service does not assess for FASD. Autism Service – if there are any concerns, and it has not already been diagnosed, contact is made with the GP to suggest a referral regarding possible FASD
Comment from National FASD: On their website, this Trust leads with its commitment to improving care – "While we are very proud of the quality improvement we have achieved to date, in the spirit of continuous improvement and striving for perfect care, we recognise there is always room for more." Yet its response shows that they have chosen to not take action on NICE QS 204. The Trust considers itself compliant with the parts of NICE QS 204 that it has deemed relevant to their work – Statements 1, 2 and 3. This Trust's review sheet states that Statements 4 and 5 are not relevant to their Trust. SIGN 156, the source guideline for NICE QS 204, states that prenatal alcohol exposure should be 'actively considered' as a possible cause for neurodevelopmental delay, so this means that there will be many in their services for whom FASD is currently not being considered as a possible underlying cause of the challenges and health issues their staff are supporting. Its response regarding diagnosis demonstrates a focus on those with facial features, which are less than 10% of those with FASD. The Trust has not indicated any FASD training nor is it planning to use NICE QS 204 indicators to measure improvement of care to avoid alcohol exposed pregnancies and recognise and manage care for those with FASD.

MID AND SOUTH ESSEX NHS FOUNDATION TRUST

Response
Q1 - Yes it has been circulated by the Clinical Effectiveness Team to maternity and paediatric teams
Q2 - Maternity and Paediatric teams (Lead: Doctor, with input from site based alcohol and drug midwives)
Q3 - a) children and young people (aged 0 to 25) – Yes; b) children and young people with special educational needs and disability – No; c) safeguarding (all-ages) – Yes; d. learning disability and autism (all-ages) – No
Q4 - Yes – please see attached file
Q5 - N/A
Q6 - Electronic records mean that the Trust can audit the questions around alcohol consumption/number of units and advice given. Stakeholders can give feedback around the service, but this is not asked specifically around the Drug and alcohol service.
Q7 - Awaiting clarification
Q8 - You may wish to direct your request to the NHS Mid and South Essex Integrated Care Board for this information
Q9 - FASD is seen and followed up by Paediatricians. If in doubt, the Paediatricians request a Geneticist to see the patient and confirm diagnosis. But the diagnosis is mainly history, based on maternal alcohol abuse, facial features and with poor growth. There is no particular lead as each Paediatrician has their own patients. This does not need any special skills to manage and can be managed under general paediatrics.
Comment from National FASD: This Trust provided a review sheet that indicates with the exception of Statement 2 they have no need for further improvement in care or tracking of indicators for Statements 1-5 as called for in NICE QS 204. The review sheet indicates only specialist midwives would note alcohol use (this then is only focused on those using higher amounts of alcohol, which his counter to NICE QS 204 best practice. The review sheet does say they can "request that this is added as a mandatory question on our ante natal workflow on the maternity system. This would then allow evidence to be obtained when required" but it is unclear if that means they will change practice to ask about alcohol use at all appointments as stated in Statement 2. The response is silent on whether written information is provided. The Trust's reply about how diagnosis is made demonstrates a lack of awareness of the latest diagnostic guideline – SIGN 156 – which outlines a more detailed criteria for diagnosis and which is the basis for NICE QS 204 so it is unclear how they might be able to consider themselves in compliance with Statements 3 and 4. Their response does not indicate any FASD specific training has been undertaken and no "Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations" was provided.

MID CHESHIRE HOSPITALS NHS FOUNDATION TRUST

Response

MIDLANDS PARTNERSHIP NHS FOUNDATION TRUST

Response
(Delivery failure)

MID YORKSHIRE HOSPITALS NHS TRUST

Response

MILTON KEYNES UNIVERSITY HOSPITAL NHS FOUNDATION TRUST

Response
Q1 – No
Q2 – 3 - Please contact the ICB - Freedom of

Information - BLMK Integrated Care Board (icb.nhs.uk)
Q4 - We have not been able to confirm if this has occurred.
Q5 - This will be completed with the relevant departments within the Trust.
Q6 - We have not been able to confirm if this has occurred, however our Maternity Voices Partnership supports reviews to guidelines and other documents.
Q7 - No
Q8 - Please contact the ICB Freedom of Information - BLMK Integrated Care Board (icb.nhs.uk)
Q9 - In Neonates, maternal history and clinical features would be looked for during NIPE (Newborn Infant Physical Examination) which all babies undergo in the first 72 hours of life. Any concerning features would be escalated to the Neonatal Consultant and follow-up arranged in that consultant's clinic. As at least a few of these babies are also looked after children, this cohort would be reviewed by the Community Paediatrician lead clinician for Looked After Children.
Comment from National FASD – This Trust has not demonstrated it is taking action on NICE QS 204. It had not identified any FASD training for staff across services nor has it set in place means to track improvement of services using the indicators provided in NICE QS 204. Its response regarding diagnosis demonstrates it is only focused on those with facial features, which are less than 10% of those with FASD. This Trust's services include maternity, antenatal clinic, obstetrics and gynaecology, neonatal, mental health, speech and language and occupational therapy, physiotherapy, cardiology, ophthalmology, and more – all of these services have a role to play in recognising and managing care for people with FASD.

MOORFIELDS EYE HOSPITAL NHS FOUNDATION TRUST

Response

THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

Response
Q1 - Yes. QS204 was circulated to the Trust's Women's Services, Paediatric and Therapy Services Directorates.
Q2 - Women's Services, Paediatrics and Therapy Services Directorates.
Q3 - Yes. System-wide work is currently underway in Newcastle-Gateshead, by a FASD working group (including partners from Mental Health Services, Local Authorities, Foundation Trusts and colleagues from the North East and North Cumbria Integrated Care Board), to submit a proposal to operationalise standard assessments and recommendations to children and young people affected by alcohol in utero across the locality.
Q4 – [extra document provided, Maternity: Drugs including Alcohol in Pregnancy]
Q5 - Please see above.
Q6 - Some members of the system-side working group have also attended the North-East and North Cumbria FASD Task and Finish group where parent/carers of young people affected by alcohol in utero views on assessment and support options within the region are shared and these contributions have been considered and added into the draft proposal.
Q7 – [extra document provided, NICE QS 204 update]
Q8 - There is currently no commissioned pathway in place however a draft proposal is in development.
Q9 - There is currently no dedicated assessment pathway for children with suspected FASD to be assessed. Instead, children are assessed by the service deemed best suited to a child/ younger person's neurodevelopmental differences, which would include a health and developmental assessment.
Comment from National FASD: This Trust is taking action and has a multidisciplinary working group on FASD underway which is encouraging. The documents provided say they are not compliant with Statements 3-5 and that, "It is recognised that there is a need for a dedicated FASD service. System-wide work is currently underway, in Newcastle-Gateshead, by a FASD working group (including partners from Mental Health Services, Local Authorities, Foundation Trusts and colleagues from the North East and North Cumbria Integrated Care Board), to submit a proposal to operationalise standard assessments and recommendations to children and young people affected by alcohol in utero. The draft proposal also considers the views of parents and carers of young people affected by alcohol in utero." Their NICE QS 204 update states they are compliant with Statements 1 and 2 – while they do say they discuss and record AEP through the pregnancy, they don't mention providing written material to women at appointments. In the information given it was disappointing to see the phrase ' Process for identifying women during the antenatal period who have a drug or alcohol problem' because most women in the UK drink alcohol and as the CMOs' guidance is that there is no known safe level of alcohol in pregnancy, a women does not need to be a dependent or 'problem' drinker for this to be relevant. One of the other questions was, 'Do you drink alcohol now that you are pregnant? How often? How much?' this may be problematic as nearly half of pregnancies are unplanned and the question may not be clear about alcohol exposure pre-pregnancy recognition. The phrase 'Women who admit to using substances' is used which does not adhere to the FASD: Preferred UK Language Guide which recommends using the factual phrasing, 'alcohol-exposed pregnancy'. The details given suggest an AUDIT-C is used with all women but looking at the scoring a woman could drink 5 units 2-3 times a week and be considered lower risk which does not follow the CMOs' guidance. It also is not clear what training plans are in place, or if the intention is to track improvements over time as called for in NICE QS 204.

NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

NORFOLK AND SUFFOLK NHS FOUNDATION TRUST

Response

Q-19 - Norfolk and Suffolk NHS Foundation Trust is a Mental Health Trust. It would appear that the questions you have asked relate to an Acute Hospital rather than a Mental Health Trust. Therefore I have closed your request down as the questions do not apply to this Trust or the services we provide therefore we do not hold the information you have requested.

Comment from National FASD: This Trust has not taken action and does not indicate in its response that its services may well be needed in care management of someone with FASD. Some 90% of people with FASD have mental health challenges (Streissguth et al., 2004). It has not indicated its staff have any FASD training as called for in NICE QS 204.

NORFOLK COMMUNITY HEALTH AND CARE TRUST

Response

Q1 - It was reviewed with representatives from all places and was forwarded to our Specialist, System Operations and Childrens Services Quality team for review.

Q2 - It was circulated to our children's teams and deemed for awareness and for paediatricians for training.

Q3 - Guidance was forwarded to team leads, and shared for awareness. Having liaised with our senior lead nurse and nursing colleagues the implementation of the NICE guidance around advice about alcohol consumption during pregnancy for a person with an LD would still come from the midwife with support where needed around communication needs from a member of the LD team.

Q4 - We do not have a record of individual breakdowns of NICE guidance, we have one master spreadsheet which covers all NICE guidance for the trust and is not appropriate to send.

Q5 - As standard, we review NICE guidance in the NICE Steering group meeting, circulate guidance to relevant departments who review and complete pro forma documents indicating impact and how the guidance will be followed within the department. This is then reviewed at Clinical Effectiveness Quality Improvement group

Q6 - We do not have anything specific to this NICE guidance, but we involve stakeholders in our NICE guidance reviews via the CEQIG meeting and involve patients via the Patient Experience Groups and Friends and Family Feedback forms and our Quality Assurance Tools.

Q7 – No

Q8 - The Trust has not been separately commissioned to provide a FASD diagnosis service. Any further questions should be directed to the Integrated Care Board (ICB).

Q9 - The child would be referred in and would be offered an appointment with a community paediatrician who would take a history and examine the child and may seek additional information from other sources such as school and consider whether any further investigations are needed. The paediatrician may also seek an opinion from a clinical geneticist as they have expertise in assessing for the facial and other features that may be present in FASD. We have no specific processes for assessing for FASD within the adult LD service.

Comment from National FASD: This Trust - which includes Community Paediatrics, Looked After Children service, a Neurodevelopmental Service, an ADHD service, OT, SALT and more services which all have a role to play in recognising and supporting people with FASD - has not demonstrated it is taking any specific action to improve its quality of care or to track their improvements using the indicators, following NICE QS 204 and states clearly they are not commissioned to provide services for FASD diagnosis.

NORTH BRISTOL NHS TRUST

Response

NORTH CUMBRIA INTEGRATED CARE NHS FOUNDATION TRUST

Response

Q1 - Yes to all Children's services and Maternity

Q2 - Community Paediatrics and Midwives

Q3 - Reference to substance misuse and related issues as part of Trust policies for safeguarding, Learning Disabilities - published on the NCIC Staff intranet. Maternity Ante Natal booking guidelines; Substance Misuse in Maternity – care for women- published on the NCIC staff intranet. 7 minute briefing guides published on the staff intranet – safeguarding site for: Self Neglect adults; Think Family; Neglect; Early Help and ACES. We use the resources/ leaflets available (FASD UK alliance, national organisation for FASD) to support parents / carer of children diagnosed with FAS (foetal alcohol syndrome) and FASD (foetal alcohol spectrum disorders) SIGN 156 and NICE QS204. Community paediatrics do see these children if they are referred for a developmental assessment and a management plan put in place. This may involve Children's Community Nursing services input as part of the MDT e.g. SALT/ OT who are able to provide care. Resources/ leaflets used are via: National Organisation for Foetal Alcohol Syndrome-UK (councilfordisabledchildren.org.uk) Home - National FASD www.nofas-uk.org

Q4 - Please see attached

Q5 -

Q6 - Patient experience feedback is encouraged

throughout the organisation. Any compliments, patient feedback or complaints are tracked and managed via our Patient Experience and Complaints teams.
Q7 - See documents referred to in answer 3.
Q8 – No
Q9 - Parents/ carers can self- refer by contacting their local child development centre. Children can also be referred by GPs' health visitors, child minders, nurseries or schools. A list of the Child Development Centres and contact details are available on the Trust Public Website – see link below: Child Development: North Cumbria Integrated Care (ncic.nhs.uk). Our multidisciplinary team are able to help children and young people with a range of health and developmental problems. These include children with: a diagnosed disability chronic illness; special or complex needs; We can also help those who have fallen behind or their developmental milestones. Your first appointment usually lasts about 1 hour. During the appointment we'll ask you some questions about your child's history and assess what their needs are. Together we'll create a care plan and some goals for your child. Parents/ carers and children might also get invited to appointments for: a parents and carers group; joint therapy sessions with other members of our multidisciplinary team; a review to see how your child is getting on. These could be in a clinic, their home or your child's nursery or school.
Comment from National FASD - This Trust has circulated the NICE QS 204 but has not determined any further actions needed. Their response indicates they have been sharing some information about FASD and that some are diagnosed locally, and that is encouraging. However, their response does not indicate any FASD-specific training across services as called for in the QS, so it is difficult to know if their staff are using best practice. In reference to Statements 1 and 2, the antenatal booking guideline has a separate section on smoking but not alcohol and does not refer to NICE QS 204 or PHE Maternity High Impact report on alcohol. They also have not indicated they are providing pregnant women with written information as called for in NICE QS 204. The Trust states that FASD is not commissioned and it's unclear if prenatal alcohol exposure is "actively considered" as a cause for neurodevelopmental delay as called for in SIGN 156. Their reference in their response to Fetal Alcohol Syndrome diagnoses demonstrates they are not fully on board with SIGN 156 diagnostic guidelines. They have not indicated any further action to improve quality of care is needed or will be tracked on their review sheet.

NORTH EAST AMBULANCE SERVICE NHS FOUNDATION TRUST

Response

Q1-9 - As an ambulance service this NICE standard does not apply to the Trust and therefore, we do not hold the information you have requested. However, please find the following Acute and Mental Health Trusts for the North East area covered by the North East Ambulance Service NHS FT (NEAS). The hospital addresses are publicly available through their respective websites, and they may hold the information you are seeking: Northumbria Healthcare NHS FT Newcastle Upon Tyne Hospitals NHS FT City Hospitals Sunderland NHS FT; South Tyneside NHS FT; County Durham & Darlington NHS FT North Tees & Hartlepool Hospitals NHS FT South Tees Hospitals NHS FT; Tees, Esk & Wear Valleys NHS FT Northumberland, Tyne &Wear NHS FT Gateshead Health NHS FT
Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

NORTH EAST LONDON NHS FOUNDATION TRUST

Response

NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST

Response

NORTH STAFFORDSHIRE COMBINED HEALTHCARE NHS TRUST

Response

Q1-9 - The Trust is not commissioned and do not provide any services for Fetal Alcohol Spectrum Disorder so unable to respond to the request.
Comment from National FASD – This Trust's website says, "North Staffordshire Combined Healthcare NHS Trust is a leading provider of mental health, social care, learning disability and substance misuse services in the West Midlands." It states it conducts assessments and treatments for children with learning disabilities, runs a CAMHS Autistic Spectrum Disorder service, has community drug and alcohol services, has adult ASD and mental health services. It is inconceivable that they do not have people with unrecognised and unsupported FASD in their services though they have not indicated any plans to take action to improve the quality of care they offer. Some 90% of people with FASD have mental health challenges (Streissguth et al., 2004). Their reply does not indicate they have taken any steps to implement staff training as called for in NICE QS204 nor have they recognised their role in Statement 5 management of those with FASD, especially at key stages of transition.

NORTH TEES AND HARTLEPOOL NHS FOUNDATION TRUST

Response

NORTH WEST AMBULANCE SERVICE NHS TRUST

Response

Q1-9 - As we are an emergency ambulance service, the trust does not have the information you require.

Comment from National FASD – Whilst we recognise this is a specialist Trust, people with FASD use ambulances in time of need as part of their care and for example the Trust has not indicated its staff have had any training. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

North West Anglia NHS Foundation Trust

Response

Q1 - Yes, the NICE guidance was circulated to our obstetric, neonatal and paediatric teams

Q2 - Parts of the standard were relevant to each of the teams.

Q3 - a. children and young people (aged 0 to 25); n/a; b. children and young people with special educational needs and disability; n/a; c. safeguarding (all-ages); and n/a d. learning disability and autism (all-ages) n/a

Q4 - Please see attached a summary version with relevant comments.

Q5 - See above

Q6 - For applicable statements, audits are undertaken according to the department annual Clinical Audit plan. In addition, spot checks will be carried out as part of the guideline below.

Q7 - The Trust is updating its "Substance Misuse in Pregnancy" guideline which specifically references alcohol use in pregnancy and the fetal effects of this. This document is currently going through our internal governance and approval processes and is therefore in draft form so cannot be shared at this time.

Q8 - Neurodevelopmental assessments and management plans are done by the Community Paediatric team which is not part of this Trust.

Q9 – Maternity - 6-8 week Booking Appointment – a discussion would be held with the patient about various clinical issues, part of which includes a discussion regarding excessive alcohol consumption; 12-18 weeks Consultant led referral – if the patient has a history of alcohol abuse, a consultant appointment referral will be made to initiate consultant led care for the duration of the pregnancy; Paediatrics - Children and young people are referred by our paediatric team to the community team as necessary for assessment.

Comment from National FASD – This Trust is taking some action to update its 'Substance Misuse in Pregnancy' guidelines but it has not indicated any staff training as called for in NICE QS 204, and as a result it's not clear they are following current guidelines, they say on their review sheet that their K2 portal explains "fetal alcohol syndrome" – which is outdated terminology and only refers to less than 10% of those with FASD. They also state women are advised to drink 'no more than 1 unit a week' – which is not the CMOs guideline which states the safest approach is no alcohol. In addition, the Trust has not indicated the cross sector training as called for in NICE QS 204, as other practitioners throughout the Trust – including in A&E, neurology, cardiology, imaging and other departments may well be involved in care management of those with FASD as called for in Statement 5.

NORTHAMPTON GENERAL HOSPITAL NHS TRUST

Response

NORTHAMPTONSHIRE HEALTHCARE NHS FOUNDATION TRUST

Response

Q1 - Yes

Q2 - Community Paediatrics, ASD ADHD TEAM, CTPLD

Q3 - CYP 0-18/19 if at special schools in relation to a,b,c,d. The Turst's FASD pathway document is applicable to all these groups and is attached for reference.

Q4 - No review sheet available

Q5 - See Q3

Q6 - Patient experience was previously tracked via IWGC (I Want Great Care) but has recently transferred to IQVIA

Q7 - See Q3

Q8 – No

Q9 - see attachment NHFT FASD Pathway

Comment from National FASD: This Trust provided a draft FASD pathway and that is encouraging. The draft pathway that they provided is not clear they have plan in place regarding care management as per Statement 5. Their pathway states, "Once assessments have been completed, routine follow up with Community Paediatrics will not be offered unless clinically indicated; eg reassessment of children at risk of FASD." While the pathway for diagnosis is positive, the Trust did not provide any further information on how other services such as sexual health, mental health, Looked After Children, community paediatrics, speech and language, occupational therapy and more are improving their quality of care to prevent, recognise and manage care for FASD. They did not demonstrate they are using the indicators in NICE QS 204 to track improvements over time, nor did they discuss multi service FASD training.

NORTHERN CARE ALLIANCE NHS FOUNDATION TRUST

Response

Q1 - This was circulated when published. It was also within the public health study day. Updates and discussions regarding NICE Standard 204 take place annually on the Level 3 Safeguarding study day.
Q2 - Applicable to maternity (statement 1&2) for advice to all women, specifically applicable for enhanced continuity of care under ROMES team for women who either have a FASD diagnosis, undiagnosed neurological challenges or women who consume alcohol during pregnancy.
Q3 – CPS - The Trust are able to offer an assessment for FASD where concerns have been raised about alcohol intake during pregnancy. Often this is noted during Children Looked after medical assessments but have also assessed children within the developmental clinics. In terms of future planning there is no formal pathway in Oldham. A meeting took place on 4th March 2024 to discuss a pathway devised by one of the consultants, but it was recognised that cross system working will be required, particularly with CAMHS team and this may need new commissioning agreements. In the interim the Trust will continue to review requests via triage for developmental assessment and children looked after medical assessment. ADNS Safeguarding Children - The Trust is not aware of any 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. Learning Disability and Autism - As above.
Q4 - Please see question 5.
Q5 - All women are asked at booking appointment regarding their personal alcohol intake and that of their partner. This is re-visited during the pregnancy and documented via their electronic record. If women are identified as consuming alcohol at any point they are referred to the specialist ROMES team for continuity and support.
Q6 - Women on the ROMEs pathway report to feeling comfortable discussing honestly their alcohol consumption to their named midwife due to the relationship formed between them. This enables further referrals to support services to be made.
Q7 - For incorporation into clinical guideline CPWC039 and CPWC275.
Q8 - There is currently no formal pathway for FASD at present.
Q9 - Per point 3. For maternity care per the booking process which is standardised nationally. If FASD diagnosis disclosed referral to ROMES offered and referral to GP with consent for further discussion and assessment pathway.
Comment from National FASD – This Trust's response shows mixed success in improving services as called for in NICE QS 204. The response indicates plans for development of a pathway, though notes the need for commissioning changes. There was no indication that some of the teams have taken action on NICE QS 204. It is encouraging to see positive stakeholder feedback noted regarding discussions of alcohol use in pregnancy. The Trust has not commented on cross service training as called for in NICE QS 204, nor has it said it plans to track the indicators provided in NICE QS 204. The response does not indicate the full range of services available in this Trust are aware of their role in recognition and management of care for those with FASD and the need for training.

NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST

Response

Note: response included 2 Quality Standard Template documents that both state the Trust is fully
Q1 - Yes, the quality standard was shared with the Trust's Family Services Division and was reviewed by the obstetrics and the children's services specialties.
Q2 - The Governance lead for the Family Services Division confirmed that the quality standard 204 was applicable to the obstetrics and the children's services specialties.
Q3 - a. children and young people (aged 0 to 25); From a paediatric perspective this is not a service we deliver locally, and the local paediatricians would refer to Sheffield; b. children and young people with special educational needs and disability; In respect of babies and children looked after 0 – 18
years of age (including those placed for adoption) who may have diagnosed/ undiagnosed SEN/ Disability/ EHCP/ LD/ Autism: • Statutory health assessment within 20 working days of becoming looked after; Recommendations for referral for exposure to FASD can be evidenced in health care plans if identified; • Parental health history; obstetric and neonatal history
is reviewed as part of the Comprehensive Statutory Initial health assessment. Exposure to maternal alcohol use may be picked up at this point if shared/known. All children seen every six months for statutory
health assessment until age 5 and annually thereafter. This is an opportunity for any further behavioural challenges, new maternal alcohol in pregnancy history, to be picked up and consideration for exposure to FASD made and reflected in health care plan; • Continual scrutiny/chronologies during the care experience
may yield further information that indicates maternal alcohol use, often because of health assessments, risk management meetings, strategy meetings following concerning behaviour, learning difficulties, physical symptoms. Scrutiny of health recommendations from health plans as part of the CLA review process to the IRO ensure no gaps in health drift occur. • In North East Lincolnshire, referrals to 'special package of care' can be made to the Humber and North Yorkshire ICB for consideration of additional assessment (including neurodevelopment assessment) and/or therapeutic intervention which may capture children with presenting challenge which may be due to exposure to maternal alcohol use is contributory to the concerns. • Consideration is given to referral (by social worker or GP) to refer to Surrey and Borders Partnership

NHS Foundation Trust ([7]www.fasdclinic.com) but there are funding costs and a long waiting list. They accept referrals from across the UK. Referral for genetic screening is required to be made locally, prior to the FASD assessment being carried out. Local genetics services are centrally funded by the NHS and the national genomic testing service is delivered through a network of seven Genomic Laboratory Hubs (GLHs), each responsible for coordinating services for a particular part of the country. • For those children and young people (including care leavers up to age 25 years) where exposure to alcohol use in pregnancy is evident children looked after health team will work with partners across child and adult services recommend neurodevelopmental assessment if there are clinical concerns. This may be providing health chronologies/History and being part of MDT meetings across children and adult services including planning for transition to adulthood. • The Paediatric service would receive referrals from GP for behavioural concerns of children that may have maternal alcohol use in pregnancy upon history taking. CLA teams across North and North East Lincolnshire consist of: • Designated Doctor children looked after and care leavers/ medical advisor for adoption/ Consultant Paediatrician; • Speciality Doctor; • Senior Named Nurse; • Named Nurse; • Specialist Nurses; • Admin support c. safeguarding (all-ages); c - The safeguarding children / midwifery team are available to support the Trust in identifying any safeguarding concerns related to FASD and would support the making of appropriate referrals to local authority children services if parental / carer alcohol use was impacting on children who are seen within the Trust. Safeguarding children training covers substance misuse and the impact on babies / infants / children and the midwifery documentation asks about substance use, which includes alcohol, to all women during pregnancy. The Trust employs three safeguarding midwives (2 Named Midwives and 1 Specialist Midwife) who support all midwifery staff in identifying safeguarding concerns which includes substance misuse during pregnancy. d. learning disability and autism (all-ages) this is not a service provided by NLaG, we would support an adult with FASD if they were an inpatient with another illness but don't provide anything in terms of service provision specifically for FASD.
Q4 - Baseline assessment completed as attached.
Q5 - Baseline assessment completed as attached.
Q6 - N/A
Q7 – No
Q8 - ICB have not commissioned FASD service from NLAG. However, a significant % of babies and children become looked after due to parental alcohol use and the impact on parenting and therefore forms part of the commissioned children looked after service (NLAG N and NEL) to undertake comprehensive statutory health assessments, working across the partnership to meet the health, social and educational needs of children looked after.
Q9 - There is no process for a child with possible FASD to be assessed within the Trust. However if the child with developmental delay when being investigated by the paediatrician, there is information about maternal alcohol intake in pregnancy, the paediatrician will request additional assessments (cognitive /speech and language) and will diagnose if it fulfils NICE criteria and has phenotypical features.
compliant in all aspect of the NICE QS with no identified improvements planned.
Comment from National FASD – This Trust has conducted a review and considers itself fully compliant with NICE QS 204 and therefore apparently has not set goals for improvement of care which is a concern. It has not commented on the call for training that runs throughout the NICE QS, so it is difficult to know if awareness and best practice is indeed system wide and through the relevant teams. There is no local pathway for diagnosis and they note the added cost and delay that entails.

NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST

Response
Q1 - Yes – This quality standard was circulated to all Business Units in the Trust in March 2022.
Q2 - This Quality Standard has been confirmed as being relevant to Maternity Services and SCBU (Special Care Baby Unit).
Q3 - All pregnant women will be asked about alcohol in pregnancy, the amount of alcohol and frequency, if a positive result is obtained in pregnancy they will be referred into the MDT. They will also receive appointments with the high-risk midwife and offered other services. This may also include the necessary safeguarding referrals and trust engagement and involvement in multiagency processes and pathways. Toxicology will be taken at every appointment. If toxicology's come back positive the patient will be given a care plan and discussed in MDT at least on three occasions during her pregnancy. The trust has just updated screening in toxicology which allows a greater window for detection of alcohol expanding the window for detection for up to three days. This includes learning disability and autism as part of the pathways. The trust are signed up to the learning disability/autism diamond standards and there is an acute liaison learning disability and autism service who will link in with the community learning disability team if any intervention required.
Q4 – Review sheet provided
Q5 – N/A
Q6 - This is not recorded information.
Q7 - No
Q8 - There is no ICB-commissioned service for FASD.
Q9 - The usual process would be a new patient clinic appointment to gather information on drug and alcohol exposure, history of developmental concerns and to assess for facial features of alcohol using the Washington scales for lip philtrum depth and upper lip thickness and measurement of palpebral fissure length using the Washington Excel calculator and Stromland data set. Further testing eg SNP array +/- MRI brain would be undertaken. Information gathered from SLT, ed psych, school to ascertain if significant impairment in

3 + of the 10 domains of assessment.
Comment from National FASD: This Trust has assessed its compliance with NICE QS 204. The Child Health Community response is that it is in full compliance with Statements 3 and 4 and that Statement 5 is not relevant. Maternity response indicates full compliance with Statements 1 and 2. The response does not indicate additional FASD training as called for in NICE QS 204 nor does it show they are tracking improvement in quality of care using indicators provided by NICE.

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST

Response

NOTTINGHAMSHIRE HEALTHCARE NHS TRUST

Response
Q1 - All newly published quality standards and other NICE guidance are included in a weekly bulletin circulated to staff across the Trust by the NICE Team. The bulletin includes links to the quality standard so that staff are able to familiarise themselves with the guidance quickly. The bulletin that included QS204 was circulated on 17 March 2022 and is attached in Appendix 1.
Q2 - The quality standard was discussed for relevance and review/action at the bimonthly NICE Group meetings in May 2022. The Groups, which include representatives from all Care Groups and other clinical services, agreed that the quality standard was not relevant to Forensic Services (FS), was relevant to Community Health Services (CHS) but was unsure about the impact/relevance for Mental Health Services (MHS). A full review was conducted by CHS and a baseline assessment completed confirming the Care Group's compliance on 11 July. The Trust Head of Nursing, Quality and Patient Experience, SSD confirmed that the quality standard was not relevant to SSD on 20 September 2022.
Q3 - CHS review of QS204 FASD - The quality standard covers the assessing and diagnosing of fetal alcohol spectrum disorder (FASD) which does not apply to the 0-19 Healthy Families Programme. However, the standard also covers support during pregnancy could apply to the 0-19 service from 28 weeks of pregnancy in the context of the antenatal visit which is a mandated review/assessment as part of the commissioned service. This does not supersede the midwifery service, this is a health promotion contact, an introduction to the service and a baseline assessment of need. There are only 2 statements which could apply to the 0-19 service: - 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. Health Visitors at the antenatal contact will discuss alcohol consumption as part of their baseline assessment. If a problem is identified or a potential risk, they will discuss the risk of harm to the baby, signpost to relevant information on RECAP and/ or make a referral to Change, Live, Grow alcohol support service if this hasn't already been done by the midwifery service. Statement 3 - Children and young people with probable prenatal alcohol exposure and significant physical, developmental, or Behavioural difficulties are referred for assessment. This does apply; however, the service is unable to make a referral directly to a paediatrician for a detailed assessment but do refer the parent back to the GP to undertake a decision to refer or the 0-19 practitioner could refer the child to the Small Steps Service for behaviour associated with Autistic Spectrum or Attention Deficit Disorder. Statement 4 & 5 is not applicable to Nottinghamshire Healthcare NHS Foundation Trust
Q4-Q5 - See attached baseline assessment in Appendix 2.
Q6 - The Trust has strong links with the Patient Involvement team and is working closely with them to ensure the patient voice is heard when implementing NICE recommendations.
Q7 - No further documentation
Q8 - Information is held by NHS Nottingham and Nottinghamshire Integrated Care Board We advise you contact them directly – please see link below for your information: Home - NHS Nottingham and Nottinghamshire ICB
Q9 - Please see our Trust response in question 3 above. Please note the main response is that the Health Visitor would refer to the GP.
Comment from National FASD – This Trust has not indicated it is taking any action specific to improvements called for in NICE QS 204. In its supporting documents, this Trust reports that NICE QS 204 of is of "low relevance" and marked the Trust as "compliant". They note health visitors have a role to ask about alcohol exposure as part of their contact, and this is encouraging though the response is silent on whether or not this is being recorded as per Statement 2. This is perhaps due to commissioning issues as it appears from the reply their 0-19 service can refer to other services for support for ASD and ADHD but not FASD. This Trust has services for ADHD, a neurodevelopmental specialist service, CAMHS, a Children's Looked After team, occupational therapy, speech and language therapy and more. In other words, there will be relevance and a need for FASD training across services and tracking of improvement of quality of care as called for in NICE QS 204.

OXFORD HEALTH NHS FOUNDATION TRUST

Response
Q1 - Yes, at time of release but following a scoping of guidance compliance we re-circulated in 1st Feb 2024. This guidance was part of 34 that were moved and asked for re-benchmarking on AMaT.
Q2 – Q4 . See attached report from our AMaT system
Q5 - N/A
Q6 - See attached report from our AMaT system
Q7. Not at present – although easy read leaflets about

alcohol consumption are being created by our learning disabilities colleagues.
Q8. The Trust does not hold this information and advises contacting BOB ICB.
Q9. See attached report from our AMaT system
Comment from National FASD: This Trust has taken partial action. They have sought input from across services as to how it applies and that is encouraging and have identified its relevance to several services. Particularly encouraging is their statement from their Learning Disability Community Service – "they will be implementing easy read information on use of alcohol in pregnancy as a result of this review."
Their report from their AMaT system states, in reference to Statement 1 "Pregnant women are given advice throughout pregnancy not to drink alcohol " that "this is not relevant to HV service as visit happens towards the end of pregnancy (after 32 weeks). And the Health Visitor service also said in reference to Statement 2 "this is also not relevant to HV service as conversations do happen with pregnant women but not throughout the pregnancy." This is counter to NICE QS 204 and the CMOs guidance because the baby's brain and CNS is still developing and vulnerable to alcohol exposure throughout the entire pregnancy. The Mental Health Service states, "The Quality Statements primarily refer to the care provided by antenatal services and is therefore not directly relevant to our directorate." While they recognise some pregnant women will be in their service, their reply doesn't take into account people with FASD who might be in their service and their role in a management plan as called for in Statement 5. It is not clear what cross service training on FASD is occurring per NICE QS 204.

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

OXLEAS NHS FOUNDATION TRUST

Response
Q1 - The Quality Standard (QS) was circulated to the Community Paediatrics teams when it was published in March 2022.
Q2 - Oxleas Community Paediatrics Teams in Greenwich and Bexley.
Q3 - Within Community Paediatrics (0-16 years; 18 years for SG/LAC/SN schools), FASD has been considered in our service provision. Diagnostic algorithm for FASD attached – Doc 1.
Q4 - Please see attached NICE standardised template for Community paediatrics – Doc 2.
Q5 - Review sheet attached as above.
Q6 - Patient experience is regularly requested and reviewed each month at team meetings for all services. Additionally, we are planning to present to stakeholders this year specifically for the NICE Quality Standard 204
Q7 - FASD Audit August 2022 attached – Doc 3.
Diagnostic algorithm for FASD (attached in Question 3 response).
Q8 - A diagnostic pathway is embedded within our general commissioned Community Paediatric services. Specific pathway commissioning queries should be addressed to the ICB.
Q9 - Children who may be referred with the query of FASD or likely FASD are identified by clinicians during initial assessments (e.g., neurodevelopmental concerns, development and learning delay, safeguarding medicals, Looked after Children or Adoption medicals). All initial assessments include history taking which includes Prenatal/Birth history, specific questions are asked to elicit Prenatal Alcohol Exposure at each initial appointment. Children under five years have developmental assessments and those over 5 years have detailed history of their level of functioning in the developmental domains. Children are examined including growth measurements taken. After Initial appointment, children are referred for assessment for possible ASD, ADHD, DCD. Referrals are also made to Speech and Language Therapists, Physiotherapists, Occupational Therapists as appropriate. When carrying out an assessment for FASD, a clinician collates all the information from various assessments and therapy reports, reviews any genetics results as required, obtains reports from Educational Psychology Assessments. The clinician then collates this information and, if indicative, confirms FASD diagnosis, as appropriate and writes the report. Patients and carers are then linked to FASD support groups.
Comment from National FASD - This Trust's response indicates it is taking action and that is encouraging. For example, in its review sheet it notes, "All doctors in the [Community Paediatrics] team to develop further knowledge of FASD so that all are able to pick it up and make appropriate refs. 1-2 doctors to develop further expertise to be able to diagnose FASD. Dr XX to start seeing children for FASD diagnosis." This was completed and they note that an "Audit/Survey planned based on this QS" was also completed. The audit identifies some action to be taken, i.e. "Ensure we are asking about antenatal alcohol exposure – for all patients to have clear documentation of this. Clarify best/most appropriate way to do this – lifestyle survey questionnaire in office." They plan to redo their audit in one year's time. However the response is silent on cross service training and continuing monitoring of improvement in services based on indicators provided in NICE QS 204.

PENNINE CARE NHS FOUNDATION TRUST

Response

PORTSMOUTH HOSPITALS UNIVERSITY NHS TRUST

Response

THE PRINCESS ALEXANDRA HOSPITAL NHS TRUST

Response

THE QUEEN ELIZABETH HOSPITAL, KING'S LYNN, NHS FOUNDATION TRUST

Response

QUEEN VICTORIA NHS FOUNDATION TRUST

Response

Q1 – Yes

Q2 - In June 2022, QVH paediatric ward manager deemed QS204 - Fetal alcohol spectrum disorder not applicable to the Trust

Q3 – 9 – Unanswered

Comment from National FASD – Whilst we recognise this is a specialist trust providing "reconstructive surgery, burns care and rehabilitation services for people who have been damaged or disfigured through accidents or disease" people with FASD may well rely on them as part of their care management. The Trust has not indicated its staff has had FASD training as called for in NICE QS 204.

THE ROBERT JONES AND AGNES HUNT ORTHOPAEDIC HOSPITAL NHS FOUNDATION TRUST

Response

Q1—9 - We are a specialist orthopaedic Trust with no A&E or Maternity Unit and we wouldn't deal with patients with this disorder.

Comment from National FASD – This Trust is not taking action on NICE QS 204. Whilst we recognise it is a specialist trust, people with FASD do use these services as FASD can involve bone issues resulting from prenatal alcohol exposure and the Trust has not demonstrated its staff have had the training called for in NICE QS 204 should they be involved in care management for someone with FASD.

ROTHERHAM DONCASTER AND SOUTH HUMBER NHS FOUNDATION TRUST

Response

Q1-9 - RDaSH is a Mental Health and Community Services NHS Trust and does not provide midwifery services (*FoIA s1(1) Information Not Held*). The following Acute Trusts may be able to provide the information you require. Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust, North Lincolnshire and Goole NHS Foundation Trust, Rotherham NHS Foundation Trust

Comment from National FASD: This Trust has not recognised in its response its role in recognising and managing care for those with FASD and the importance of staff training as called for in NICE QS 204. More than 90% of people with FASD present with mental health issues. (Streissguth et al., 2004) Their CAMHS, ADHD, Looked After Children's Health, Learning Disability Crisis and Intense Support, continence services and many others will undoubtedly include people with FASD who according to NICE QS 204 Statements 3-5 should be appropriate assessed and supported. Their health visitors and alcohol support units will need training in Statements 1 and 2 as women who could become pregnant or who might be pregnant are likely accessing those services.

THE ROTHERHAM NHS FOUNDATION

Response

Q1 – Yes

Q2 - O&G, CYPS

Q3 - (On behalf of CYPS department): a) Yes; b) Yes; c) Yes; d) <5 Yes, >=5 No, CAMHS lead on this. If over 5 years there is no current pathway for neurodevelopmental assessment

Q4 - See Baseline Assessment attached

Q5 - (On behalf of CYPS department): As we are not contracted to deliver this pathway for over 5s, the QS204 recommendations will be used to negotiate future pathway and this deviation from NICE will added to the risk register

Q6 - In terms of the patient experience the community CYP service will seek feedback through parent / carer forum.

Q7 – No

Q8 – No

Q9 - The process for an assessment of possible FASD is dependent on the child's age and to what degree their development is affected. Child under 5 with more than one area of developmental delay:

Children can be referred into this service by portage, health visitor, GP or other clinician. The child can be assessed in the child development centre to establish the cause of their developmental delay. Staff in CDC have access to occupational therapy, physiotherapy, speech and language therapy (competent in neurodevelopmental assessment of autism), neuro-imaging. Consultants in Child Development Centre (CDC) have access to further training in the diagnosis of FASD.

Child under 5 with one area of developmental delay or no developmental delay: Children can be referred to this service by their GP.

The child is referred to the general paediatric team, and can be assessed for features of FASD and microcephaly. If further developmental delay is then identified the child can be referred to CDC for assessment. Child over 5

In order for children over 5 to have an assessment for FASD they invariably need access to a team who can provide assessment of all 10 neurodevelopmental areas. The child can be referred to community paediatrics for an assessment of facial features of FASD, an assessment of alcohol history and clinical examination. Separate referrals would be required through school for an educational psychologist assessment,

neurodevelopmental assessment of autism or ADHD by CAMHS. If a child has already had these assessments prior to being seen by a community paediatrician, it would be possible to make a diagnosis at this assessment.
Comment from National FASD: This Trust states that it is in full compliance with Statements 1 and 2 but their baseline assessment only mentions that alcohol in pregnancy is noted at booking "or when disclosed". It does not state that this is discussed throughout pregnancy or that there is written material provided. It states that Statements 3-5 are 'not applicable" which is not the case, as this Trust's services include cardiology, a child development centre, continence advisory, looked after children, occupational therapy, ophthalmology, orthopaedics, physiotherapy, speech and language therapy and more. The response highlights implies that Statement 4 is not being met in current services, as a neurodevelopmental assessment is typically only possible after the age of 5. On the positive side it states that NICEQS 204 will be used to negotiate a future pathway and this deviation from NICE will be added to the risk register.

ROYAL BERKSHIRE NHS FOUNDATION TRUST

Response

ROYAL CORNWALL HOSPITALS NHS TRUST

Response

ROYAL DEVON UNIVERSITY HEALTHCARE NHS FOUNDATION TRUST

Response

ROYAL FREE LONDON NHS FOUNDATION TRUST

Response
(Delivery error)

THE ROYAL MARSDEN NHS FOUNDATION TRUST

Response
Q1 – 9 – The Royal Marsden is a world-leading cancer centre specialising in cancer diagnosis, treatment, research and education. We have two hospitals: one in Chelsea, London and another in Sutton, Surrey. We also have a Medical Day care Unit in Kingston. We are partners with The Institute of Cancer Research and are the provider of Sutton and Merton Community Services. The information which you have requested is not relevant to the Trust since the Trust does not operate a paediatric service.
Comment from National FASD: While we recognise the specialist nature of this Trust, their staff will still need training, people with FASD get cancer and the Trust may well be part of care management.

ROYAL NATIONAL ORTHOPAEDIC HOSPITAL NHS TRUST

Response
Q1-9 Please note that our Trust provides orthopaedic services only and we do not consider that this FOI request applies to our hospital.
Comment from National FASD – This Trust is not taking action on NICE QS 204. Whilst we recognise it is a specialist trust, people with FASD do use these services as FASD can involve bone issues as a result of prenatal alcohol exposure and the Trust has not demonstrated its staff have had the training called for in NICE QS 204 should they be involved in care management for someone with FASD.

THE ROYAL ORTHOPAEDIC HOSPITAL NHS FOUNDATION TRUST

Response
Q1-9 - The Royal Orthopaedic Hospital is an elective orthopaedic hospital and does not provide such services or have these departments.
We are therefore unable to provide any further information for this Freedom of Information request.
Comment from National FASD – This Trust is not taking action on NICE QS 204. Whilst we recognise it is a specialist trust, people with FASD do use these services as FASD can involve bone issues as a result of prenatal alcohol exposure and the Trust has not demonstrated its staff have had the training called for in NICE QS 204 should they be involved in care management for someone with FASD.

ROYAL PAPWORTH HOSPITAL NHS FOUNDATION TRUST

Response
Q1-9 - Royal Papworth Hospital NHS Foundation Trust is a specialist cardiothoracic hospital; therefore these questions are not applicable.
Comment from National FASD: Whilst we recognise the specialist nature of this Trust, we note that people with FASD often have cardiothoracic challenges as a result of prenatal alcohol exposure and their staff may well be called upon to participate in care management as noted in Statement 5 and this Trust has not indicated it is ensuring any staff training on FASD. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

ROYAL SURREY NHS FOUNDATION TRUST

Response

Q1 - Yes, the guidance was circulated in 2022
Q2 - Please see guideline attached (accessible by clicking 'response' above)
Q3 – Yes
Q4 - N/A
Q5 - Please see guideline attached
Q6 - N/A
Q7 - N/A
Q8 - This information is held by Surrey Heartlands Please send your request directly to them: https://www.surreyheartlandsccg.nhs.uk/
Q9 - Please see attached guideline.
Comment from National FASD - This Trust's reply has not demonstrated a specific response to NICE QS 204. The guideline attached on substance misuse in pregnancy does not include the best practice indicated by NICE QS 204 Statements 1 and 2. It refers to alcohol misuse without providing information that all pregnant women are given verbal and written information including the CMO guidance (2016) about prenatal alcohol exposure, are asked throughout pregnancy and the information recorded. The response is silent on Statements 3-5 or training as called for in NICE QS 204.

ROYAL UNITED HOSPITALS BATH NHS FOUNDATION TRUST

Response

THE ROYAL WOLVERHAMPTON NHS TRUST

Response

SALISBURY NHS FOUNDATION TRUST

Response

SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST

Response

SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST

Response

Q1 - Yes – all new/updated guidance gets sent to all care groups and following CAEC all relevant guidance gets sent to the relevant colleagues.
Q2 - Care Group leads.
Q3 - As per baseline assessment, yes they have.
Q4 - Baseline assessment wasn't completed in this way – each statement of the QS was commented on to show how the service meets these recommendations.
Q5 - See Above
Q6 - See Above
Q7 – N/A
Q8 – No
Q9 – See above
Comment from National FASD – This Trust's response included a baseline assessment that indicates it is taking some partial action in line with NICE QS 204 but it does not indicate what steps have been taken regarding the training as called for throughout NICE QS. It also is silent on plans to use NICE QS 204 indicators to assess improvements in quality of services.

SHEFFIELD HEALTH AND SOCIAL CARE NHS FOUNDATION TRUST

Response

Q1 - Yes, the relevant services are aware of this quality standard.
Q2 - The key services are Perinatal Mental Health and the Health Inclusion Team.
Q3 - a) We do not provide children's services, and though people accessing adult services will fall within part of this age range there is no overall Trust lead. b) N/A c) and d) All relevant NICE guidance is taken into consideration when developing service specifications and clinical pathways, alongside commissioners assessments of local need and decisions regarding service provision.
Q4 - This NICE Quality Standard is taken into account, alongside all NICE Quality Standards, as providing guidance on priority areas for improvement. QS204 is of partial relevance to some of our services and as such we are not tracking any particular improvements related to this.
Q5 - Both the Perinatal Mental /health and Health Inclusion teams have accessed training on FASD.
Q6 - QS204 is of partial relevance to some of our services and as such we are not tracking any particular improvements related to this.
Q7 - QS204 is of partial relevance to some of our services and as such we are not tracking any particular improvements related to this.
Q8 - This falls within the scope of children's services and is not a commissioned pathway in this Trust.
Q9 - We are not the Trust responsible for such assessments and would refer to the Community Paediatric Service or liaise with the GP.
Comment from National FASD: The Trust has taken some steps to share the NICE QS 204, has accessed some training and recognises that adults with FASD would fall under their care, however they are not tracking improvements in this area, have not identified any FASD lead, and have no commissioned pathway for adults with FASD. It is also unclear what their practices are NICE QS 204 statements 1 and 2.

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

Response

SHERWOOD FOREST HOSPITALS NHS FOUNDATION TRUST

Response

THE SHREWSBURY AND TELFORD HOSPITAL NHS TRUST

Response

Q1 - All NICE guidance that is relevant to the Trust is circulated to all staff in the Trust following publication.
Q2 - The benchmark assessment template for QS 204 was completed by the Deputy Director of Midwifery. Statements 1 and 2 relate to the Trust and the Trust is recorded as meeting these requirements, with no further action required. Statements 3 to 5 have been deemed not applicable to the Trust.
Q3 - The Trust does not hold this information as it does not provide this service. Under Section 16 of the Freedom of Information Act (2000) we recognise our duty to assist you in locating the information described in your request. This service is carried out by the Shropshire Community Trust and we therefore recommend that your request is redirected to their FOI team, [2] Freedom of Information - how to make a request (shropscommunityhealth.nhs.uk)
Q4 – Q7 – N/A
Q8 - The Trust does not hold this information. We would recommend that you
contact the ICB FOI team via
https://www.shropshiretelfordandwrekin.nhs.uk/about-us/how-we-are-run/polices-procedures-and-governance/freedom-of-information/
Q9 - The Trust does not hold this information as it does not provide this service. We would recommend that you contact the ICB FOI team via
https://www.shropshiretelfordandwrekin.nhs.uk/about-us/how-we-are-run/polices-procedures-and-governance/freedom-of-information/
Comment from National FASD: This Trust has full maternity, neonatal and children's services, endocrinology, speech and language therapy, neurology, occupational therapy, paediatrics, among other services. It has stated that it is in compliance with Statements 1 and 2 but has not indicated any staff training to ensure that their maternity teams are fully briefed on latest guidance and best practice. Nor has it set any further action to use the quality indicators in the NICE QS to assess improvements.

SHROPSHIRE COMMUNITY HEALTH NHS TRUST

Response

Q1 - This quality standard was circulated in April 2022 to all services within Children and Young People's Division in line with the standardised Trust process for the dissemination and implementation of NICE guidance.
Q2 - Community Paediatrics Service; 0-19 Public Health Nursing Practitioner Service
Q3 - Trust overview: The Trust provides public health nursing input (Health Visitors and School Nurses) via the 0-19 Public Health Nursing Practitioner (PHNP) service for the population of Shropshire Telford and Wrekin, following the Healthy Child Programme. The Trust provides Community Paediatrician and Therapy Services for children with developmental difficulties from 0-16 and 0-19 for people with a learning disability and/or physical disability. The Trust provides Community Nursing for patients with a nursing need. The Trust has a large SEND (Special Education Needs and Disabilities) population of patients and is the main provider for advice requested by the two local authorities in Shropshire as part of EHCNA (Educational Health and Care Needs Assessment) process. The Trust follows its statutory duties for safeguarding. Involvement in all aspects of safeguarding from recognition, support, early help through to child-in-need and child protection conferences and plans from all services as appropriate.
Q4 - A baseline assessment of compliance for each relevant service was undertaken during 2022using the quality standard service improvement template published by NICE. [Note – we could not open this, request to resend was not successful in time for publication.]
Q5 – n/a
Q6 - Early discussions with Public Health Nurses and Midwifery. Training for staff - Community Paediatrics (September 23), LAC nurses (October 23) and Health Visitors. A survey of staff within Children and Young People's services about baseline knowledge highlighted a request for more training across the Trust.
An audit around the identification of FASD risk in LAC is in progress. Discussion has taken place with Educational Psychology. CAMHS have been contacted to request further discussion but no response to date. FASD Information and awareness resources are being developed on the Healthier Together platform. This is a platform co-produced with parents. The STW Integrated Care System has an established neurodiversity workstream which has attendance from a range of partners including education, health, social care, voluntary sector and representatives from both the Shropshire and Telford and Wrekin SEND Parent Carer Forums. The neurodiversity workstream has been focused on support for those who have or may have Autism or ADHD, however there is ongoing discussion about whether the workstream could be expanded to support those with FASD. This is currently under consideration within the workstream. If FASD is included in the workstream, parent carer co-production will be facilitated by the SEND parent carer forums. This will be discussed further with the Children's Commissioner.
Q7 - Trust FASD guideline; Trust FASD SOP; FASD staff survey report [Note – we could not open these, request to resend was not successful in time for publication.]
Q8 - No, to date such a pathway has not been commissioned.
Q9 - Patients are referred to Community Paediatrics for assessment of cause of developmental difficulties or

seen for Initial Health Assessment for LAC will have a general assessment which will include for features of FASD. Community Paediatricians will accept referrals for consideration of FASD specifically. There are often difficulties obtaining a history of exposure to alcohol during the antenatal period (especially in the looked after population) and so unless there are sentinel facial features present it is often not possible to make a diagnosis. We do not have access to a clinical psychologist meaning there are limited neurodevelopment domains that we can assess. In under five year olds we have access to multidisciplinary assessment for autism but in older children these assessments and ADHD assessments take place in a different trust. If the domains we are able to assess are not significantly affected we cannot make the diagnosis. Similarly we cannot comment on the impact of all domains on the young person even if we can make the diagnosis. There is inadequate access to all the necessary MDT making it difficult for us to provide a comprehensive assessment and tease out any other factors.

Comment from National FASD: This Trust is taking a series of measures based on NICE QS 204 to improve its services, and that is encouraging to see, including training especially working with parent-carer forum and other efforts to engage stakeholders. Documents provided include a baseline assessment; Trust FASD guideline; Trust FASD SOP; and FASD staff survey report which demonstrate a level of attention that is promising. Unfortunately we were unable to access the documents provided.

SOLENT NHS TRUST

Response

Q1 - Yes – our service shares a list of updated and new NICE guidelines and Quality Standards every month with individual services and can confirm that this Quality Standard was shared with teams on 12th April 2022.
Q2 - Our 0-19 public health nursing services identified that this was relevant to their services for awareness.
Q3 - As per Q1, the quality standard has been shared with teams. The decision making regarding how this is incorporated within local provision would primarily sit with commissions of our services. None of our services are commissioned to specifically provide a FASD offer.
Q4 - In line with our Trust policy on NICE guidelines, as the service had highlighted that this QS was relevant at awareness level only, a baseline assessment was not completed. We have 3 levels of relevance, awareness, partial relevance and core relevance, and a baseline assessment is indicated only for core relevance (although is optional for partial relevance).
Q5 - Please see response to question 4.
Q6 - We are not.
Q7 – None
Q8 - No. However, many of our services will encounter children with FASD who have been referred for other health needs.
Q9 - FASD may be present in children who receive support/health interventions for other conditions within our community paediatric, public health or child and adolescent mental health services. We don't assess for or diagnose FASD as a discrete condition.

Comment from National FASD – This Trust, as it notes in its reply has many services that will be called upon to support FASD recognition, diagnosis and care management as called for in NICE QS 204. This includes among other services, their CAMHS team, children in care team, children's therapy services which include OT, SALT, and physiotherapy, their health visitors team, learning disability services, safeguarding, specialist dental services and more. And yet, the Trust has only flagged this for 'awareness' – which means according to information they provide, they are not tracking any improvements in quality of care as called for in NICE QS 204. They highlight there is no FASD service commissioned and they clearly state they do not diagnose for FASD despite the new SIGN 156 diagnostic guidelines and improvements called for in NICE QS 204.

SOMERSET NHS FOUNDATION TRUST

Response

SOUTH CENTRAL AMBULANCE SERVICE NHS FOUNDATION TRUST

Response

Q1-9 In our case, we are an emergency service, and as this guideline is focussed on the assessment and recognition of Fetal Alcohol Syndrome, not on pre-hospital emergency care, it has been deemed that it is not directly applicable to our staff.

Comment from National FASD – Whilst we recognise this is a specialist Trust, people with FASD use ambulances in time of need as part of their care and for example the Trust has not indicated its staff have had any training. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

SOUTH EAST COAST AMBULANCE SERVICE NHS FOUNDATION TRUST

Response

Q1-9 - We are an Ambulance Trust and therefore we are unable to answer these questions as they are not relevant to the service that we provide.

Comment from National FASD – Whilst we recognise this is a specialist Trust, people with FASD use ambulances in time of need as part of their care and for example the Trust has not indicated its staff have had any training. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

SOUTH LONDON AND MAUDSLEY NHS FOUNDATION TRUST

Response

SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

Response

Q1 - This would be the responsibility of the Commissioners, but we have circulated to community paediatricians within the Trust and the Public Health Midwife.
Q2 - Community Paediatric Service, Community paediatrics, general paediatrics, Looked after and adoption teams, Autism assessment team, Public Health Midwife. Leads for CCH. LAC and Adoption.
Q3 - Included within differential diagnoses for all children presenting with developmental difficulties with learning (aged 0 to 16 as per inclusion criteria for community child health and general paediatrics). Included within differential diagnosis for all children being assessed for autistic spectrum disorder in the preschool under 5s service. Please note that those five and above will be assessed by the neurodevelopmental team. Trust lead for community child health, safeguarding and looked after children is part of the FASD working collaborative currently liaising with members of the multidisciplinary team and multi agency team and commissioners with more specific FASD assessment pathway development. All children presenting with learning needs have access to needs lead services both within health and education and support from the local session services such as Daisy chain
Q4 - In progress in conjunction with Commissioners
Q5 - Currently working with commissioners and running a pilot study to identify specific assessments required, multi agency input required including time allocation and specific interventions and support. Additional training for lead clinicians ongoing.
Q6 - The Community Child Health team are currently working with commissioners and other specialists such as psychology re developing a specific pathway for FASD. This will be a multiagency approach and is in its early stages, the pathway will be reviewed and details shared with parent/carer groups for review.
Q7 - No other documents have been created.
Q8 - No separate pathway has been commissioned, the expectation is that the pathway is picked up as part of the paediatric community pathway. The Community Child Health team are currently working with commissioners and other specialists such as psychology re developing a specific pathway for FASD. This will be a multiagency approach and is in its early stages.
Q9 - Children with developmental, learning and behavioural difficulties where alcohol is a contributory causal factor are currently are seen within either CCH or CAMHS with a needs led approach and supported by services according to need within health, education and support for family such as Daisy Chain.
Comment from National FASD – This Trust indicates it is taking action, it is working on a pathway for diagnosis, possibly as part of the paediatric community pathway. Commissioners are engaged, a pilot study is underway and a multiagency approach is being considered. The Trust does not mention any specific training as called for under NICE QS 204 or plans to track improvements over time using NICE QS 204 indicators.

SOUTH TYNESIDE AND SUNDERLAND NHS FOUNDATION TRUST

Response

Q1 - We do not hold the information requested. Please refer you request to the following: North East and Cumbria ICB. The address for emails is necsu.ICBfoi@nhs.net; Information Governance Team, North of England Commissioning Support, John Snow House, Durham University Science Park, Durham, DH1 3YG. However, we can confirm that the Quality Standard has been circulated to Community Child Health, Maternity, Neonatal and Neurodisability Services within Trust. NENC ICB.
Q2 - We do not hold the information requested. Please refer you request to the following: North East and Cumbria ICB; The address for emails is necsu.ICBfoi@nhs.net; Information Governance Team; North of England Commissioning Support; John Snow House, Durham University Science Park, Durham DH1 3YG.
Q3 - ICB leading FASD task and finish group. Sunderland place audit of standards attached
Q4 - Audit attached – completed at request of ICB
Q5 - as above - gap analyses of NICE standards is being coordinated by the NENC ICB FASD task and finish group
Q6 - This is being coordinated and led by ICB
Q7 - Following regional guidance – attached
Q8 - No but educational psychologist assessment commissioned on case by case basis
Q9 - See attached regional guidance – referral from any health professional to FASD clinic led by two community child health consultant paediatricians with expertise in FASD
Comment from National FASD – This Trust notes the ICB is leading implementation of NICE QS 204 via an FASD task and finish group and mentions steps toward a regional strategy, a neurodevelopmental pathway which includes development of regional support for diagnoses more difficult cases. These steps are encouraging. This Trust provided one of the few review sheets that is tracking the NICE QS indicators to develop evidence of its efforts to improve quality of care. It indicates a 98% rate of discussion of alcohol use in appointments, yielding a rate of alcohol-exposed pregnancies of .5%. In the absence of any indication in the report of training for maternity teams, it is not clear that the latest best practice regarding how to have these conversations is being followed as this rate is extremely low compared to statistics that show UK alcohol exposed pregnancy rates

above 40%. They highlight that 0% of people with FASD have care management plans and highlight this as an action point as part of a ND pathway development. They have not indicated how their extended services for everything from mental health, neurology, occupational therapy, speech and language, physiotherapy and other services have been receiving FASD specific training as they all may play a role in FASD recognition, diagnosis and care management as called for in NICE QS 204 and SIGN 156.

SOUTH WARWICKSHIRE NHS FOUNDATION TRUST

Response

Q1 - The NICE guidance QS 204 on Fetal Alcohol Spectrum Disorder was distributed to all divisions/teams
Q2 - The Teams that said it was relevant for them were 1. Obstetrics 2. Acute Paediatrics and 3. Community Paediatrics
Q3 - Obstetrics and Acute Paediatrics confirmed that the Trust is fully compliant with Quality Standards 1 and 2. Community and neurodevelopmental team are in the early stages of developing a pathway
Q4 - The Trust is not yet fully compliant with Quality Standards 3 4 and 5.
Q5 - There is no designated FASD service either in community paediatrics or CAMHS Neurodevelopment team – this is the common situation around the country, however, Community and neurodevelopmental team are in the early stages of developing a pathway
Q6 - A Community Consultant Paediatrician has an interest and has had some additional training in assessing and the Community and neurodevelopmental team pathway is in the early stages
Q7 - Quality Standard 5 essentially is a robust Education Health and Care Plan but this needs developing
Q8 – The Consultant Paediatrician has commenced discussions with the neurodevelopment team. It is early stages but there is a desire to build a service
Q9 - Referred to acute or community team if clinical features. If antenatally high risk infant then followed up directly from SCBU.
Comment from National FASD – This Trust reports that they are not compliant with Statements 3-5 but are working towards a local pathway involving a paediatrician who has had extra training and that is encouraging. The Trust states that it is fully compliant with Statements 1 and 2 but it does not indicate maternity teams have had training as called for in NICE QS 204 nor evidenced that they are proving written information for patients, nor that it is using indicators provided by NICE to track improvement in these services.

SOUTH WEST LONDON AND ST GEORGE'S MENTAL HEALTH NHS TRUST

Response

SOUTH WEST YORKSHIRE PARTNERSHIP NHS FOUNDATION TRUST

Response

Q1-9 - South West Yorkshire Partnership NHS Foundation Trust is a specialist NHS Foundation Trust that provides community, mental health and learning disability services to the people of Barnsley, Calderdale, Kirklees and Wakefield. We also provide some medium secure (forensic) services to the whole of Yorkshire and the Humber. The Trust represents only a small element of healthcare in our area and does not provide these services and therefore does not hold the information you have requested. You may wish to redirect your request to the local acute hospitals who may be able to assist you. In respect of the geography we cover, local acute NHS Trusts are: Mid Yorkshire Hospitals NHS Trust, Calderdale and Huddersfield NHS Foundation Trust, Barnsley Hospital NHS Foundation Trust
Comment from National FASD – This Trust states clearly it does not consider NICE QS 204 to be relevant, despite the fact they are providing community, mental health, learning disability and forensic services. Their practitioners will undoubtedly come into contact with people with undiagnosed or diagnosed FASD and they will need FASD informed training as called for in NICE QS 204 and will at the very least be involved in Statement 5 care management but also contributing to identification of those at risk. SIGN 156 the source guidance says that prenatal alcohol exposure should be 'actively considered' as a cause for neurodevelopmental delay. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

SOUTH WESTERN AMBULANCE SERVICE NHS FOUNDATION TRUST

Response

Q1-9 - This guideline was determined as not applicable and therefore no further actions were taken.
Comment from National FASD – Whilst we recognise this is a specialist Trust, people with FASD use ambulances in time of need as part of their care and for example the Trust has not indicated its staff have had any training. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

SOUTHERN HEALTH NHS FOUNDATION TRUST

Response

SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST

Response

ST GEORGE'S UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Response

Q1 - No but the clinical audit and effectiveness team will send this out imminently.
Q2 - SGH paediatric teams, including neonatal service, paediatric neuro-developmental service, neuro disability service and the maternity for quality statements 1 and 2
Q3 - At risk neonates/infants from birth will be flagged up and followed up for assessment through the neonate follow up pathway and then as indicated into the developmental service. If they fulfil criteria, they will be referred for FASD assessment as below. As part of our comprehensive assessment we provide in the children's Neuro-developmental service, all children with developmental concerns will have a thorough history and assessment including birth history where FASD will be considered as a potential cause. If FASD is a possibility, they will be referred as per question 8 for tertiary assessment but ongoing support for their behavioural needs will be provided. Currently we have only 3 patients which is a very small number (will cover all of Wandsworth) and new diagnosis rate averages less than 1/year. As a result the current pathway would be sufficient; following referral to FASD ongoing service provision as advised can be provided via the current service provision.
Q4 - Not Applicable
Q5 - We will review the NICE standard in detail and outline changes if any to our current service provision based on our service load of maximum 2-3 patients at anytime with diagnosis rates of less than 1/year.
Q6 - NICE Quality Standard 204 will be disseminated to leads and following that review will outline what implementations and review would look like
Q7 – None
Q8 - Please contact South West London Integrated Care Board
Q9 - At risk infants will be flagged via the obstetric pathway and communicated to neonatal teams if risk has been picked up. If a child is born not picked up but is dysmorphic and raises suspicion for FASD, they will be assessed as part of the new born screening and referred for genetic testing to exclude a genetic cause and will be followed up in the neonatal clinic as appropriate (or referred to their local paediatric or neonatal clinic for follow up in out of area). If they present as older children, they are referred with suspected FASD to the tertiary FASD team at Redhill (Surrey and Borders NHS Trust) for assessment. They provide a diagnostic assessment and behaviour management guidance to support local services. Their details are as below: Fetal Alcohol Spectrum Disorders (FASD) Specialist Clinic, Gatton Place, St Matthew's Road, Redhill RH1 1TA. Their referral criteria are: Age over 6 years (with clinical suspicion of FASD); Genetic testing completed or underway; Funding agreement in place with the CCG with PO number included
Comment from National FASD – This Trust says it will now review NICE QS 204 'in detail' which is encouraging. This Trust's website states it is "one of London's leading teaching hospitals with an international reputation for quality of care and cutting-edge treatment." Its services include a neurosciences department, audiology, cardiology, a full range of paediatric specialist services (including paediatric neurodevelopmental service), and others – all of which might be involved in helping to recognise and support those with FASD per Statements 3-5. Their gynaecology and maternity services will be involved in Statements 1-2. The Trust has not identified any actions to date to improve its quality of services as outlined in NICE QS 204, has not indicated it's providing FASD-specific training for its staff across services, nor has it indicated it will track improvement in services using the indicators provided by NICE QS 204. While it is encouraging that there is provision for some referrals to the National FASD service, the fact this Trust states they have a diagnosis rate of less than 1 per year (when conservative estimates are FASD has a 2-4% prevalence rate) demonstrates they are likely missing many with FASD who are in their services and highlights the need for FASD-specific training on the latest SIGN 156 diagnostic guidelines and best practice as outlined in NICE QS 204 rather than demonstrating, as they claim, that there is no need for a change in the current pathway.

STOCKPORT NHS FOUNDATION TRUST

Response

SURREY AND BORDERS PARTNERSHIP NHS FOUNDATION TRUST

Response

SURREY AND SUSSEX HEALTHCARE NHS TRUST

Response

SUSSEX COMMUNITY NHS FOUNDATION TRUST

Response

SUSSEX PARTNERSHIP NHS FOUNDATION TRUST

Response

Q1 - There has been a targeted circulation of this quality standard within the Trust. This guidance has been circulated to all staff in the Perinatal Service. The CAMHS service and Children's Neurodevelopmental service have considered the guidance. This guidance had not been circulated to other services.

Q2 - The CAMHS Service, the Perinatal Service and the Learning Disabilities and Neurodevelopmental services have identified these standards as applicable to them.
Q3 - The Trust has not been commissioned to offer specialist assessments for FASD. The consideration for assessment of local need and service provision lies with the commissioners for the service and not with the trust. A) and B) There has been specific training for the CAMHS Neurodevelopmental Service, psychiatrists and psychologists in CAMHS on FASD following this guidance. Child and Young People who are identified as needing assessment are referred to specialist services for assessment. C) The Named Doctor for safeguarding has joined multi-agency discussions about the structuring of access to external specialist commissioning as part of the ICB work which has been lead by the Designated Doctor for looked after Children. D) In Learning Disabilities Services: - If someone had this diagnosis we would consider a person-centred pathway as we would anyone else who had a known diagnosis. In the Adult NDS this diagnosis is considered as part of the ND assessment process but there has been no additional training, or changes that have been made as a result of this guidance.
Q4 - This is not available.
Q5 - There has been a program of training on FASD in CAMHS and Children's neurodevelopmental Service to improve recognition as part of the CAMHS Training Program. Specialist assessment services are not commissioned to be provided by the trust.
Q6 - They have not been involved up to this point.
Q7 - No.
Q8 - There is access to specialist FASD assessment services via low volume commissioning.
Q9 - If possible FASD was identified then the person would be referred to a specialist service via low volume commissioning or on a named [sic].
Comment from National FASD – This Trust has taken some action, including engaging in ICB-level discussions about commissioning and training for CAMHS, perinatal services and LD/ND disability services which is encouraging. However, its response does not indicate that the Trust is tracking improvements in care by using the indicators provided by NICE QS 204 and this combined with the ICB response above implies they are still referring for specialist assessment to the Surrey specialist service and considering this to be 'low volume' despite the prevalence rates. Its response is silent on any improvements in care in their perinatal service based on NICE QS 204.

TAMESIDE AND GLOSSOP INTEGRATED CARE NHS FOUNDATION TRUST

Response

TAVISTOCK AND PORTMAN NHS FOUNDATION TRUST

Response
Q1-9 - The Tavistock and Portman NHS Foundation Trust is a small specialist mental health Trust, and not a hospital. We provide outpatient, and mainly psychological, services. We do not provide acute services, nor inpatient services, and do not have an A&E department. We do not offer a dedicated Service for patients with Fetal Alcohol Spectrum Disorder, though we might work with patients suffering this condition as part of their overall mental health presentation. Your request for information is not applicable to our Trust, as we do not offer the services to which NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder, published in 16 March 2022, would apply.
Comment from National FASD: This Trust has not taken action and has failed to note that their service may be required to support care management of people with FASD as called for in Statement 5. They have not indicated their staff has had any training as called for in the QS. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

TEES, ESK AND WEAR VALLEYS NHS FOUNDATION TRUST

Response
Q1 – Yes
Q2 - Our Child and Adolescent Mental Health Services (CAMHS) and Perinatal Mental Health Team were identified as key services for QS204. However, we also acknowledged that, alongside GPs and midwives, we should engage in education and information sharing to reduce the impact of alcohol in pregnancy on any child's life; we therefore agreed that QS204 should apply to all our services that engage with people who can be pregnant.
Q3 - As a mental health and learning disabilities Trust, Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) does not lead in the implementation of this Quality Standard. However, the Trust does have a role in working with wider system colleagues to support implementation by: Providing education and information for service users who can be pregnant; We screen all adult service users with the Alcohol Use Disorders Identification Test Consumption (AUDIT C - attached). Service users scoring 5+ on AUDIT C receive brief advice, which includes a caution that drinking in pregnancy can harm the developing foetus. Maintaining an awareness of FASD and FASD as a possible differential diagnosis within neurodevelopmental/ other assessments, and referring children and young people to appropriate services depending on need; We developed an information sheet on FASD (FASD Information sheet - attached) for staff which includes characteristics of FASD. The resource has been included within the CAMHS clinical competency framework, shared with all CAMHS staff, and shared with other specialties where service users could be pregnant. The Trust has also provided a series of FASD webinars hosted by the

CAMHS neuropsychologist which were open to all CAMHS staff.
Q4 - We conducted a qualitative baseline assessment – see response to question 5 below.
Q5 - Please see attached qualitative baseline assessment against QS204, including an action plan developed to address areas for improvement. Actions are monitored centrally.
Q6 - As a mental health and learning disabilities Trust our role is limited to preventative information sharing, and recognition and referral of suspected FASD. We refer cases of suspected FASD to external Specialists for assessment. We therefore do not include FASD specifically in our patient experience monitoring. We do, however, offer opportunities for all patients who come into contact with our services to share their experience, including via the Friends and Family Test (FFT), and through
our Complaints Department.
Q7 - No other documents have been produced. Our role is awareness and as such we produced the qualitative baseline assessment, fact sheet and awareness training only.
Q8 - FASD is not commissioned as a stand-alone pathway.
Q9 - At present, TEWV would not accept referral for FASD alone; patients under our care for other reasons who might benefit from FASD assessment would be referred to the local acute Trust for investigation.
Comment from National FASD – This Trust serves as a positive counter to other Mental Health Trusts that have stated NICE QS 204 is not relevant to them. This Trust has developed an FASD information sheet based on SIGN 156 and the NICE QS and webinars for CAMHS staff which is encouraging to see. That said, their response does not indicate if they are tracking improvements using the indicators provided by NICE and it is not clear what training is happening outside of CAMHS. They state that only service users scoring 5+ on AUDIT C receive brief advice when the NICE QS 204 states all pregnant women should receive this advice throughout pregnancy and including in written form. They state in their assessment, "Role for TEWV - should apply to all services that engage with people who can be pregnant. TEWV have an educational and information sharing role the same as smoking and alcohol, but in the context of the unborn child" and this also is encouraging. They also refer to the DHSC FASD Health Needs Assessment in their baseline assessment. The Trust repeatedly states that their role is 'awareness' and they don't necessarily provide evidence that people with FASD will be accessing their services – since there is a high correlation between FASD and mental health challenges – and their positive behaviour support, speech and language, physical therapy, occupational therapy and other services will all need FASD training and could well be involved in FASD recognition, diagnosis and care management. We also note women who use this Trust's services could be pregnant or become pregnant or could have FASD themselves.

TORBAY AND SOUTH DEVON NHS FOUNDATION TRUST

Response
Q1 - We do not hold this information. We don't routinely circulate NICE QS for review, instead we review them against their source guidance this is where the quality standards derived from. In this case QS204 links to NG201 (see attached). NG201 would have been circulated to Obstetrics & Gynaecology Clinical Service Lead and Governance leads and it looks like this was then shared with the community leads. In addition, the response will have been in included within the escalation packs.
Q2 - We do not hold this information.
Q3 - We do not hold this information. We don't routinely circulate NICE QS for review, instead I review them against their source guidance this is where the quality standards derived from. NG201 would have been circulated to Obstetrics & Gynaecology Clinical Service Lead and Governance leads and it looks like this was then shared with the community leads. In addition, the response will have been in included within the escalation packs.
Q4 - Please see attached local baseline assessment.
Q5 - N/A
Q6 - There is no current provision for this.
Q7 - N/A
Q8 – No
Q9 - Referral into community paediatrics, consideration of diagnosis against NICE/SIGN guidance with consultation with other specialists which may include genetics, speech therapy and educational psychology but formulation would remain with the community paediatrician.
Comment from National FASD – This Trust's response focuses only on their internal review of NG201 on antenatal care but does not reference SIGN 156 which underpins the specifics about alcohol, pregnancy and FASD. It has not demonstrated it is taking any action on Statements 3-5 and the improvements in care and cross service training on FASD, and while claiming to be complaint with Statements 1 and 2 does not show evidence that maternity teams and other relevant healthcare workers are trained in the latest best practice on alcohol and pregnancy and are providing written materials about this as called for in NICE QS 204. The Trust has not indicated it is tracking the indicators provided by NICE to demonstrate improvement of care over time. This Trust includes CAMHS, safeguarding, social care, occupational therapy, speech and language therapy, ophthalmology, neurology, child health, learning disabilities and many other services that will all be involved in helping to recognise and manage care for those with FASD.

UNITED LINCOLNSHIRE HOSPITALS NHS TRUST

Response

UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

Response

UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST

Response

Q1 - Yes – it has circulated NICE Quality Standard 204.
Q2 - Obstetrics / Maternity, Child Health
Q3 - If there are concerns of developmental delay without an obvious cause then referral for developmental delay support and diagnosis are made to the community paediatric team (separate NHS trust) from secondary care paediatrics. They have specialists who have special training for FASD able to make this diagnosis. Secondary care paediatricians have all had training that would enable detection of FASD and it is within the diagnostic possibilities when a patient is seen however referrals for developmental delay are generally directed to our community paediatric colleagues due to their expertise. We don't have any specific documents for this. We have learning difficultly and autism specialist nursing post to support these patients and families.
Q4 - We have completed copies of the Trust NICE gap analysis template which have been shared at respective governance meetings.
Q5 – n/a
Q6 - Stakeholders – the completed gap analysis forms have been shared at the relevant Trust meetings
Q7 - Local Pregnancy Substance and Alcohol use guideline. Please find attached.
Q8 - Information not held by the Trust. [Provided link to Hampshire and Isle of Wight ICB]
Q9 - Local Pregnancy Substance and Alcohol use guideline outlines observations and symptoms in the early neonatal period. On discharge from maternity services referred to child health.
Comment from National FASD: This Trust appears to be taking some positive concrete action via a gap analysis and sharing this at stakeholder meetings (though this document was not provided), but it is not clear that there is any local pathway in place for diagnosis and management. The pregnancy guideline recognises FASD but whilst the Trust have provided their clinical guidelines which show a detailed and robust guideline for substance misuse and high level alcohol use it fails to acknowledge low level drinking or early prenatal alcohol exposure. It doesn't identify the methods used by maternity teams to determine alcohol use and doesn't acknowledge whether the Trust is meeting the Quality Standards as set out in NICE QS204.

UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST

Response

UNIVERSITY HOSPITALS BRISTOL AND WESTON NHS FOUNDATION TRUST

Response

Q1 - The Quality Standard was formally cascaded 20 April 2022, to the relevant lead clinicians in Obstetrics and Midwifery.
Q2 - The Obstetrics and Midwifery teams.
Q3 - This is not directly applicable to the Trust. Children under consideration or confirmed with FASD would be seen by Sirona Care and Health and/or Avon and Wiltshire Mental Health Partnership.
Q4 - Please see the current review sheet against the Quality Standard (a short self-assessment Compliance Statement) attached. We can confirm the Trust is partially compliant (acceptable) with Quality Statements 1 and 2 of the Quality Standard pertaining to asking about and recording alcohol use in pregnancy. Our current corporate template for NICE quality standards only addresses the quality statements and does not ask for detailed information on the discretionary quality measures.
Q5 - Not applicable.
Q6 - We are not currently involving stakeholders or tracking patient experience issues pertaining to alcohol use within pregnancy, in response to QS204.
Q7 – No
Q8 - We do not hold this information. Please contact Bristol, North Somerset and South Gloucestershire Integrated Care Board (BNSSG ICB) at foi@bnssg.nhs.net for further information.
Q9 - The Trust is not commissioned to provide FASD services.
Also provided AMAT Compliance Statement
Comment from National FASD – This Trust states it has partially achieved action on Statements 1 and 2 as part of their normal clinical practice and that it has determined Statements 3-5 are not relevant. They have stated that no action is needed. However, their response does not indicate that their staff has had any training on FASD as called for in NICE QS 204 so it is unclear if they are using best practice, nor does it indicate if written information is being provided to pregnant women. They also state that only if 'high intake' is reported would they then refer to an obstetric consultant who 'may' liaise with an alcohol team who would then use a screening tool like Audit or FAST and at that point it would be recorded in patient notes. They also have not indicated the role their occupational therapists, speech and language therapists and other services might play in recognition, diagnosis and care management of those with FASD and have not indicated the need for training as called for in NICE QS 204.

UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

Response

UNIVERSITY HOSPITALS DORSET NHS FOUNDATION TRUST

Response

UNIVERSITY HOSPITALS OF DERBY AND BURTON NHS FOUNDATION TRUST

Response

Q1 - All Team members in the Specialist Midwifery Service for Pregnant People using Drugs and Alcohol have seen the Quality Standard and we incorporated this in our training program for all midwives in 2023.
Q2 - Statement 1 and 2 are specifically applicable to the Specialist Midwifery Service for Pregnant People using Drugs and Alcohol.
Q3 - The Trust's Safeguarding team have been made aware of the Quality Standard.
Q4 - There is no review sheet.
Q5 - We do not have a review sheet, however, staff have been educated regarding the Quality Standard.
Q6 – N/A
Q7 – o
Q8 - The Specialist Midwifery Service for Pregnant People using Drugs and Alcohol are not asked to make referrals for babies deemed at risk of FASD
Q9 - Should FASD be suspected, a medical review is completed either by the child/young person's community paediatrician, or hospital paediatrician, if one is involved. If there are physical features for FASD the young person is referred to Genetics. Clinical Psychology may also complete an assessment with respect to any concerns regarding autism spectrum disorder (ADS)/learning disability as a comorbid diagnosis.
Comment from National FASD – This Trust states that they have incorporated NICE QS 204 into their training for all midwives and that is encouraging. They have not indicated that they are providing pregnant people with written information nor have they stated they are tracking any of the indicators provided by NICE including the recording of alcohol exposed pregnancies and how many are later given FASD diagnoses. They have not demonstrated any improvement in services related to Statements 3-5 despite having a full range of children's services, a child development centre, occupational therapy, speech and language therapy, orthopaedics, and more all of which have a role to play in FASD recognition, diagnosis and management.

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

Response

Q1 - Yes.
Q2 - Clinical Director for Women's and Children's Services, Head of Service for Maternity, Head of Service for Obstetrics, Head of Service for Neonates, Women's and Children's Quality and Safety Board
Q3 - The Trust provides individualised care planning and Consultant-led care in all cases of suspected or confirmed FASD and the relevant Safeguarding teams are involved where appropriate. The safest approach is not to drink alcohol at all if you are pregnant. Pregnant women are asked about their
alcohol use throughout their pregnancy and this is recorded. Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for 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. Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs.
Q4 - Please see the attached NICE Guidance summary sheet.
Q5 - Not applicable.
Q6 - The Trust does not hold this information. You may like to consider contacting the Leicestershire Partnership NHS Trust to obtain this information.
Q7 - Please see attached a copy of the Trust's Guideline on Substance Misuse in Pregnancy Obstetric Guideline.
Q8 - The University Hospitals of Leicester NHS Trust does not hold this information. You might like to consider contacting the Leicester, Leicestershire and Rutland Integrated Care Board to obtain this information.
Q9 - For neonatal admissions/postnatal cases that come to the attention of neonatal services, a clinical assessment including review of maternal history is undertaken. Where a differential diagnosis of FASD exists appropriate investigations to confirm extent of multiorgan involvement is conducted and investigations (eg genetic assessment) to exclude relevant differential diagnoses conducted as clinically
indicated. Babies diagnosed with FASD are referred as appropriate, to community services for long term follow up and care. Please contact community services at Leicestershire Partnership NHS Trust for further details.
Comment from National FASD: This Trust states it is fully compliant with NICE QS 204 and point to their Substance Misuse in Pregnancy Guideline UHL Obstetric Guideline as evidence. However, that guideline contains outdated references to Fetal Alcohol Syndrome that are not in line with the latest diagnostic guideline SIGN 156 and NICE QS 204. They also emphasise 'problematic' drinking and drinking early in pregnancy when there is no known safe level of alcohol in pregnancy at any time and all PAE should be noted. The link in the obstetric guideline to a pamphlet on alcohol and substance misuse is not active and says the pamphlet is under review and appendix H in the guideline gives only very limited and outdated information about the risks of alcohol in pregnancy and refers again to Fetal Alcohol Syndrome which shows this document is not current. There is no indication in their reply that FASD-specific staff training is underway as called for in NICE QS 204. The Trust's response is silent on all the other relevant services in their Trust that have a role in FASD recognition, diagnosis and management –

including services such as occupational therapy, speech and language therapy, neurology, children's services, sleep disorders and more. Statement 4 for example calls for "Evidence of local services with healthcare professionals who have additional training in FASD".

UNIVERSITY HOSPITALS OF MORECAMBE BAY NHS FOUNDATION TRUST

Response

Q1- Our Community Paediatricians are aware of the SIGN 156 guidelines and the NICE Quality Standards (QS). To meet the NICE QS and Sign 156 guidelines, these patients need assessments, which includes assessments done by other services such as Speech and Languarge Therapists, Occupational Therapists and Psychology. We do not hold the requested information for these other services.
Q2 - As explained, FASD assessments need multi-disciplinary input from different teams. It does apply to our Community Paediatrics team, but we are only one part of what the assessment involves. We do not hold the requested information for the other services.
Q3 - Our Community Paediatrics do see children and young people (CYP) with special educational needs and disability, and we have safeguarding leads for all ages. All are aware of the NICE QS and consider this at appropriate times. Autism and Learning Disability services for the local CYP population is the responsibility of Lancashire and South Cumbria Foundation Trust so we do not hold this information.
Q4 - Please see the three attached documents: 20240126100027_risk3426fasd (2) (1).docx; 20230822134956_qsfasdspreadsheet.xlsm; 20230831084828_fasqualitystandardsreport.docx
Q5 – N/A
Q6 - Not done at present.
Q7 - No local trust document.
Q8 - There isn't a commissioned service for Fetal Alcohol Spectrum Disorder (FASD) in our ICB area.
Q9 - In the community Paediatrics team, we accept the referral for FASD. We clearly explain in our referral acceptance letter that we do not have a commissioned service for FASD, but we will see the child from a paediatric perspective. The Community Paediatric Neurodevelopmental team is only able to provide a paediatric opinion. In the absence of involvement of the other professionals, we might not always be able to arrive at a diagnosis or be in a position to make comprehensive recommendations regarding management and support needs other than from a paediatric perspective. In this regard, we would recommend that the referring person considers referring to other services such as educational psychology, speech and language therapy, clinical psychology and occupational therapy. This will enable a comprehensive assessment for FASD. If the child/young person has already been assessed by the professionals above, we would request for the reports to see if we can gather evidence of their neurodevelopmental areas of impairments to aid in the FASD assessment.

Comment from National FASD – This Trust states in its review sheet "the community paediatric team are able to offer an initial neurodevelopmental assessment, but this is not the same as having a commissioned service with input from SALT, OT, physiotherapy, psychology etc. Some of these services sit within UHMB control (SALT, OT, physiotherapy) and some sit outside, with CAMHS (psychology). A wider piece of work would be required to put a pathway in place, involving the commissioners and other services. Some meetings are already in place so the commissioners are sighted on some of the gaps in service provision, but the QS document hopefully adds some leverage to the discussions." It has identified areas to "Flag to service commissioner (for CAMHS / psychology input) and leads for aspects of service under UHMB control (OT / physiotherapy / SALT)." It has not yet put in place ways to measure outcomes per the indicators in NICE QS 204. It states some have had training but has not indicated if this is multi service as called for in NICE QS 204. They have identified as a moderate risk that "individuals who have Fetal Alcohol Spectrum Disorder will not receive a formal diagnosis due to there being no local pathway / multidisciplinary team undertaking assessment which means the patient may not receive the information and support they require." Regarding Statements 1 and 2 the trust has done an audit which they say "demonstrated that all women, across all sites, are being asked about their alcohol use during pregnancy. This is well documented by staff on Badgernet. Cross-Bay there is lower compliance with QS1, this may be due to the amalgamation of booking and first contact appointments at the RLI and WGH sites." However, their document unfortunately refers to "Fetal Alcohol Syndrome" a now outdated term which highlights the fact that they have not demonstrated they have provided or plan to provide training on the latest guidance and best practice in how to discuss alcohol with pregnant women, nor do they indicate whether pregnant women are being given written material.

UNIVERSITY HOSPITALS OF NORTH MIDLANDS NHS TRUST

Response

UNIVERSITY HOSPITALS PLYMOUTH NHS TRUST

Response

Q1 – Yes
Q2 - Maternity (Statements 1-2 of the attachment); Community Paediatrics (Statements 3-5 of the attachment)
Q3 - The Trust does not hold this information.
Q4 - Please refer to the attachment.
Q5 - Not applicable.
Q6 - The Trust does not hold this information.
Q7 - Not applicable.
Q8 - The Trust is working with the ICB and within the Plymouth locality to ensure a comprehensive

neurodiversity assessment pathway that aims to identify needs as early as possible irrespective of diagnosis and supports the graduated responses for the localities we serve, across all areas of need. It also aims to provide a multidisciplinary response to all Children and young people (CYP) with regards to assessment where required. This work is actively ongoing and pathways have not yet been finalised.
Q9 - At present: all referrals are triaged at consultant level and where there are features of or risk factors for FASD, these CYP are seen and assessed by the appropriate clinicians and management plans created according to individual needs. Advice and guidance will be given for any needs which can identified at the point of referral which may not be being met at that time. If there are relevant further assessment/ investigations these will be arranged. Multiple clinicians within the team have received specialist training in this area and it is identified as an area for which clinicians would be supported to receive additional external training. The learning from this is disseminated across the wider service in peer review discussions and local teaching/case studies. Where updates arise in national discussion, these can be brought back to this forum to enable local discussion as to how we can ensure these are actioned locally/identify any gaps in service/assessment. We recognise the specific biopsychosocial complexities of these CYP and at times the overlap with multiple additional diagnoses and work alongside specialist colleagues both within the team.
Comment from National FASD – This Trust has taken action on NICE QS 204 and states that training is underway which is encouraging as this will be especially needed if a new ND pathway is put in place to ensure FASD-informed care management is available. Their review has not identified any areas for improvement of quality of service and does not track the NICE indicators, which is disappointing. They also claim that Statement 3 is not relevant, as they say "Primary care would refer to Child Development Centre. These children are being referred to the service."

UNIVERSITY HOSPITALS SUSSEX NHS FOUNDATION TRUST

Response

VELINDRE NHS TRUST

Response
Q1-9 - Due to the nature of the services provided by the Trust, as explained below, we do not hold information relating to your request. Velindre University NHS Trust is a nationally recognised specialist centre of excellence for the provision of non-surgical oncology including radiotherapy and chemotherapy; specialist palliative care; blood transfusion; specialist immunohaematology; antenatal blood testing reference work; and transplant immunology. The Trust provides a range of specialist non-surgical oncology services to approximately 1.5 million people of South-East Wales, and to the whole of Wales for some services, working in partnership with the hospitals managed by the Local Health Boards. The Welsh Blood Service collects processes and delivers blood and blood products to hospitals across Wales. Please follow the link above to the Trusts internet site should you wish to find out more information about our services.
Comment from National FASD: While we recognise the specialist nature of this Trust, their staff will still need training, people with FASD get cancer and the Trust may well be part of care management.

WALSALL HEALTHCARE NHS TRUST

Response
Q1 – Yes
Q2 – Maternity, Paediatrics
Q3 - Not yet embedded
Q4 – review sheets provided
Q5 - Maternity recommendations fully implemented.
Q6 - Paediatrics: Collaborative working with Black Country Partnership to be considered
Q7 - Paediatrics: No
Q8 - Paediatrics: No
Q9 - Paediatrics: Upon referral child is assessed by the Community Paediatrician with interest in FASD in a clinic setting along with parent/carer; History taken and clinical examination carried out; Blood tests requested if required; Further information is obtained from the various professional involved in the care of the child, including CAMHS, School, Social Workers and any other identified Therapist; Analysis of all information is carried out by Community Paediatrician and based on the SIGN (Scottish Intercollegiate guidance) assessment for FASD is completed.
Comment from National FASD: This Trust has indicated on its review sheet that it has met statements 1 and 2 as the information is included in the substance misuse guideline and documented in Badgernet. It has not indicated however if the maternity teams have had training as called for in NICE QS 204 and they have not indicated any further action to track improvements in care using NICE QS indicators to see if they are making progress. They state a "Local pathway being developed. Referrals currently being assessed by community Paediatrician with training in FASD and multidisciplinary input to coordinate the care." Their assessment sheet states that statements 3 and 5 are met but not statement 4. They identify that resources will be needed to establish this pathway. They have not laid out intentions to use the indicators provided by NICE to track improvement in quality of care nor have they mentioned cross sector training.

THE WALTON CENTRE NHS FOUNDATION TRUST

Response

Q1-9 - I can confirm in accordance with Section 1 of the Freedom of Information Act 2000 (FOIA) that we do not hold the information you have requested as NICE QS 204 as it is not applicable for our Trust. Therefore, we cannot provide this information.

Comment from National FASD. This Trust is "the only specialist hospital trust in the UK dedicated to providing comprehensive neurology, neurosurgery, spinal and pain management services." As such, their response is disappointing as it is highly likely that they will at times be part of care management for people with FASD – a brain based disability which also can affect the development of the spine. The reply from this Trust shows no indication that they have considered the training called for in NICE QS 204.

WARRINGTON AND HALTON TEACHING HOSPITALS NHS FOUNDATION TRUST

Response

Q1 - This is applicable to a community paediatrician as it is for assessing and diagnosing fetal alcohol spectrum disorder (FASD) in children and young people. Community paediatricans in this area are under Bridgewater Community Healthcare NHS Trust.

Q2 - Not applicable to our paediatrics as it is managed by the community paediatricians. However, our maternity consultants do use in relation to fetal movement scans.

Q3 – a) We don't have leads for 0-25 and FASD implementation not applicable to us as supported by Bridgewater Community Healthcare NHS Trust community paediatricians; b) Not applicable to our trust but Bridgewater Community Healthcare NHS Trust; c) NICE FASD Quality Standard 204 not specifically referenced in hospital safeguarding policies. Assessment of local needs and service provision will be managed by Public Health / Cheshire and Merseyside Integrated Care Board; d) Not applicable to our trust but Bridgewater Community Healthcare NHS Trust.

Q4 - When the quality standard was published this was sent out to the relevant specialities for completion. Paediatrics confirmed that three statements (iii / iv / v) were not applicable to the Trust as any child / young person would be referred to the community paediatric specialist team. In relation to statement (i / ii) Women's health reviewed this and confirm that this is applicable to us and completed the quality standard template confirming that we meet the standard. The completed quality standard is attached.

Q5 - The quality standard was completed at the time and is attached.

Q6 - Paediatrics – N/A; Maternity – documented in patients' handheld records if alcohol misuse in pregnancy is identified then the patient would be cared for by a team of midwives who specialise in care for vulnerable women and their families.

Q7 - N/A

Q8 - This is for Bridgewater Community Healthcare NHS Trust as assessment and diagnosis is by community paediatricians, and not hospital paediatricians.

Q9 - This is for Bridgewater Community Healthcare NHS Trust as assessment and diagnosis is by community paediatricians, and not hospital paediatricians.

Comment from National FASD: This Trust's review sheet shows it is not taking action regarding NICE QS 204 and is not tracking the indicators provided to measure improvement of services. Their response does not indicate any cross service training as called for in NICE QS 204 and does not indicate consideration of the role of practitioners across services (for example in their ENT, occupational therapy, ophthalmology, orthopaedics and other services) to help recognise and manage care for those with FASD. Their reply regarding Statements 1 and 2 is not clear if they are asking all pregnant women throughout their pregnancies, nor if their teams have had FASD/alcohol in pregnancy training. They do not appear to be giving written information.

WELSH AMBULANCE SERVICES NHS TRUST

Response

Q1-9 - The Welsh Ambulance Services NHS Trust would not be in a position to diagnose foetal alcohol spectrum disorder and therefore the request is not applicable.

Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

WEST HERTFORDSHIRE TEACHING HOSPITALS NHS TRUST

Response

Q1-9 - The management of fetal alcohol spectrum disorder sits with community paediatrics. Please contact the Hertfordshire Community Trust.

Comment from National FASD – This Trust's website states it has a staff of almost 5,800 and sees nearly a million patients each year. Using the lower prevalence rate of 2%, that would mean some 20,000 of those patients will have FASD or undiagnosed FASD. The Trust has not taken action on NICE QS 204 despite having three hospitals including maternity services, a neonatal unit, family planning, OT, orthopaedics, acute children's and other relevant services.

WEST LONDON NHS TRUST

Response

WEST MIDLANDS AMBULANCE SERVICE UNIVERSITY NHS FOUNDATION TRUST

Response

Q1-9 - Thank you for your email. Given the context of your request I am assuming that it is not for my organisation (an ambulance service). If this is not the case, please let me know.

Comment from National FASD – While we understand this Trust is specialised, we note that NICE QS 204 calls for training across sectors. People with FASD use ambulances in time of need and rely on those staff to understand their disability. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequence.

WEST SUFFOLK NHS FOUNDATION TRUST

Response

WHITTINGTON HEALTH NHS TRUST

Response

Q1 – Yes

Q2 - Maternity Safeguarding and Foetal medicine teams.

Q3 - We do not hold this information in a centrally recorded and easily retrievable manner.

Q4 - The Quality Standard, with statement breakdown is freely available on the NICE website.

Q5 – Q6 - We do not hold this data.

Q7 – No

Q8 - We do not hold this data. We advise you to contact the ICB.

Q9 - Whilst we do not hold this information in a recorded or easily retrievable format, under our S16 obligations, the clinical service has kindly provided you with this further information: Diagnosis is based on maternal history of alcohol and presence of phenotypic features. Such diagnoses following birth are rare. Once diagnosed, these cases are addressed on an individual basis and referred to developmental Teams for follow up or cardiology, depending on individual need.

Comment from National FASD: This Trust, despite the fact it includes maternity, Children Looked After, autism and learning disability, community paediatrics and many more related services, has not demonstrated it is taking action to seek to improve its quality of care or to track those improvements by provided indicators as called for in NICE QS 204. It also does not indicate any effort to train staff across services as called for in NICE QS 204. Their response states this is a 'rare' condition, not reflecting the prevalence (2-4%) and the SIGN 156 diagnostic guideline and NICE QS 204 which call for prenatal alcohol exposure to be 'actively considered' as a cause for neurodevelopmental delay.

WIRRAL COMMUNITY HEALTH & CARE NHS FOUNDATION TRUST

Response

WIRRAL UNIVERSITY TEACHING HOSPITAL NHS FOUNDATION TRUST

Response

WORCESTERSHIRE ACUTE HOSPITALS NHS TRUST

Response

Q1 - The quality standard was received by the Worcestershire Acute Hospitals NHS Trust and the Maternity department have a guideline regarding alcohol in pregnancy was that was published in May 2023. We have taken this opportunity to reshare across the wider Trust for learning and understanding of FASD and the risks of alcohol in pregnancy.

Q2 - Any child with developmental delay would be referred to the Community Paediatricians. We would examine for dysmorphic features but wouldn't necessarily ask about prenatal alcohol consumption. Alcohol consumption in pregnancy and prior to is assessed by the maternity team at booking, and throughout pregnancy and appropriate advice, support and management organised as required.

Q3 - As we are an Acute Trust this is not applicable to us in the main and should be directed to the Community Paediatric team. We have strategies in place to support children with developmental delay in our clinics and on our inpatient ward.

Q4 - No review sheet is in place – quality standards 1 and 2 will be audited and managed by maternity; quality standards 3-5 are not applicable to us as an Acute Trust.

Q5 - As above – maternity have a guideline and compliance will be audited – the plan is for an audit to take place at the end of Q4 to capture the year since the launch of the guideline. Community Paediatrics will need to answer the other aspects for standards 3-5.

Q6 - This will form part of the maternity audit for standards 1and 2. Community Paediatrics will need to respond for standards 3-5.

Q7 - See maternity guideline attached.

Q8 - Not that Worcestershire Acute Hospitals NHS Trust are aware of.

Q9 - Patient with possible developmental delay identified. History and examination performed, and identification of dysmorphic features included in examination. Referred to Community Paediatrics if developmental delay confirmed for further assessment.

Comment from National FASD – This Trust has taken some action to review its alcohol and pregnancy guidelines but upon examination those are not in line with NICE QS 204 in that they still refer to outdated diagnoses (Fetal Alcohol Syndrome) which does not reflect SIGN 156, the current diagnostic guideline in England upon which NICE QS 204 is based. It's hoped when they redo their audit they update this. It is also unclear how they are proceeding with the training called for in NICE QS 204. They state they do not ask about AEP but do not acknowledge this is not always transferred to the child's notes nor that they are aware that it is only less than 10% of those with FASD who will have facial features.

WRIGHTINGTON, WIGAN AND LEIGH NHS FOUNDATION TRUST

Response

WYE VALLEY NHS TRUST

Response

Q1 - The quality standard was distributed to all ACOO and ACMO, as well as divisional managers and governance leads on 7th April 2022 – where Mrs A.Tahir was allocated as the lead.
Q2 - Email sent to Mrs Tahir within obs/gynae on 18th May 2022, advising of the QS204 document, the need for it to be circulated, and if required, the tools to carry out an improvement project/audit if deemed necessary.
Q3 - Our Community paediatric specialist has attended an one day RCPCH [Royal college of Paediatrics and child health] course on how to assess FASD and has delivered a teaching session for our Community Paediatrics multidisciplinary professionals along with the director of FASD UK. It also covers the NICE quality standards. They are not the lead, but Children do get referred into their clinics for assessment
Q4 - The QS204 was previously covered within NICE guideline NG201: Antenatal care guidance (Aug 2021), recommendations 1.1.2 and 1.3.10. Recommendation 1.1.2 - At the point of antenatal care referral: Provide an easy-to-complete referral form. Offer early pregnancy health and wellbeing information before the booking appointment. This should include information about modifiable factors that may affect the pregnancy, including stopping smoking, avoiding alcohol, taking supplements, and eating healthily. Ensure that the materials are available in different languages or formats such as digital, printed, braille or Easy Read. Recommendation 1.3.10 - At the first antenatal (booking) appointment, and later if appropriate, discuss alcohol consumption and follow the UK Chief Medical Officers' low-risk drinking guidelines. Explain that: there is no known safe level of alcohol consumption during pregnancy, drinking alcohol during the pregnancy can lead to long-term harm to the baby the safest approach is to avoid alcohol altogether to minimise risks to the baby. Both of which were confirmed by Antenatal and Newborn screening midwife that Wye Valley NHS Trust being in compliance with the recommendations as National information and guidance documents present to women in multiple formats and languages as needed, and the recommendations being cover in the maternity guidelines for routine antenatal care in uncomplicated pregnancy as well as information on alcohol consumption being include on the booking pathway.
Q5 - None on file with compliance or audit
Q6 - NICE guidance's are monitored by the NICE team and reported to the Trust executive board through the Clinical Effective and Audit Committee
Q7 - None on file with compliance or audit
Q8 - We are in the process of formulating our own pathway.
Q9 - Children get referred to our General Paediatric clinic and we assess as per the SIGN guideline. We do not have separate FASD clinics.
Comment from National FASD – This Trust has indicated some action on NICE QS 204 and state they are in the process of formulating a pathway, which is encouraging. They have not demonstrated their maternity teams are asking about alcohol throughout pregnancy and recording it. They have not reported they are using the indicators provided by NICE QS 204 to track improvements in care and their response is silent on management of care (Statement 5), despite having many related services, including SEND, mental health, speech and language therapy, occupational therapy and more.

York and Scarborough Teaching Hospital NHS Foundation Trust

Response

YORKSHIRE AMBULANCE SERVICE NHS TRUST

Response

Q1-9 - Yorkshire Ambulance Service NHS Trust can confirm that it does not hold this information pursuant to Section 1(1)(a) of the Freedom of Information Act 2000. NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder is not applicable to Yorkshire Ambulance Service NHS Trust as a provider of 999 emergency ambulance, NHS 111, and Non-Emergency Patient Transport services.
Comment from National FASD: Whilst we recognise this is a specialist Trust, people with FASD use ambulances and the Trust has not demonstrated any staff training has been conducted. It is key that ambulance services recognise dysregulated behaviour due to FASD, and not view it as being under the influence, a mental health crisis or being intentionally difficult. Also, sometimes people with FASD make 999 calls and do not understand the consequen

TRUSTS – RESPONSE SORTED ALPHABETICALLY (211 TOTAL)

Airedale NHS Foundation Trust has not demonstrated it is taking action

Alder Hey Children's NHS Foundation Trust is taking action

Ashford and St. Peter's Hospitals NHS Foundation Trust did not reply by the statutory deadline

Avon and Wiltshire Mental Health Partnership NHS Trust has not demonstrated it is taking action

Barking, Havering and Redbridge University Hospitals NHS Trust did not reply by the statutory deadline

Barnet, Enfield and Haringey Mental Health NHS Trust has not demonstrated it is taking action

Barnsley Hospital NHS Foundation Trust is taking partial action

Barts Health NHS Trust has not demonstrated it is taking action

Bedfordshire Hospitals NHS Foundation Trust did not reply by the statutory deadline

Birmingham and Solihull Mental Health NHS Foundation Trust has not demonstrated it is taking action

Birmingham Community Healthcare NHS Foundation Trust is taking partial action

Birmingham Women's and Children's NHS Foundation Trust did not reply by the statutory deadline

Black Country Healthcare NHS Foundation Trust did not reply by the statutory deadline

Blackpool Teaching Hospitals NHS Foundation Trust is taking partial action

Bolton NHS Foundation Trust did not reply by the statutory deadline

Bradford District Care NHS Foundation Trust did not reply by the statutory deadline

Bradford Teaching Hospitals NHS Trust did not reply by the statutory deadline

Bridgewater Community Healthcare NHS Foundation Trust did not reply by the statutory deadline

Buckinghamshire Healthcare NHS Trust did not reply by the statutory deadline

Calderdale and Huddersfield NHS Foundation Trust has not demonstrated it is taking action

Cambridge University Hospitals NHS Foundation Trust did not reply by the statutory deadline

Cambridgeshire and Peterborough NHS Foundation Trust has not demonstrated it is taking action

Cambridgeshire Community Services NHS Trust is taking partial action

Camden and Islington NHS Foundation Trust has not demonstrated it is taking action

Central and North West London NHS Foundation Trust is taking action

Central London Community Healthcare NHS Trust is taking partial action

Chelsea and Westminster Hospital NHS Foundation Trust is taking partial action

Cheshire and Wirral Partnership NHS Foundation Trust did not reply by the statutory deadline

Chesterfield Royal Hospital NHS Foundation Trust did not reply by the statutory deadline

Christie NHS Foundation Trust has not demonstrated it is taking action

Clatterbridge Cancer Centre NHS Foundation Trust has not demonstrated it is taking action

Cornwall Partnership NHS Foundation Trust is taking action

Countess of Chester Hospital NHS Foundation Trust did not reply by the statutory deadline

County Durham and Darlington NHS Foundation Trust is taking partial action

Coventry and Warwickshire Partnership NHS Trust did not reply by the statutory deadline

Croydon Health Services NHS Trust did not reply by the statutory deadline

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust has not demonstrated it is taking action

Dartford and Gravesham NHS Trust has not demonstrated it is action

Derbyshire Community Health Services NHS Foundation Trust is taking action

Derbyshire Healthcare NHS Foundation Trust has not demonstrated it is taking action

Devon Partnership NHS Trust is taking partial action

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust did not reply by the statutory deadline

Dorset County Hospital NHS Foundation Trust did not reply by the statutory deadline

Dorset HealthCare University NHS Foundation Trust has not demonstrated it is taking action

Dudley Group NHS Foundation Trust did not reply by the statutory deadline

Dudley Integrated Health and Care NHS Trust has not demonstrated it is taking action

East and North Hertfordshire NHS Trust did not reply by the statutory deadline

East Cheshire NHS Trust did not reply by the statutory deadline

East Kent Hospitals University NHS Foundation Trust did not reply by the statutory deadline

East Lancashire Hospitals NHS Trust did not reply by the statutory deadline

East London NHS Foundation Trust did not reply by the statutory deadline

East Midlands Ambulance Service NHS Trust exempted from results

East of England Ambulance Service NHS Trust exempted from results

East Suffolk and North Essex NHS Foundation Trust did not reply by the statutory deadline

East Sussex Healthcare NHS Trust did not reply by the statutory deadline

Epsom and St Helier University Hospitals NHS Trust did not reply by the statutory deadline

Essex Partnership University NHS Foundation Trust did not reply by the statutory deadline

Frimley Health NHS Foundation Trust did not reply by the statutory deadline

Gateshead Health NHS Foundation Trust did not reply by the statutory deadline

George Eliot Hospital NHS Trust has not demonstrated it is taking action

Gloucestershire Health and Care NHS Foundation Trust did not reply by the statutory deadline

Gloucestershire Hospitals NHS Foundation Trust did not reply by the statutory deadline

Great Ormond Street Hospital for Children NHS Foundation Trust did not reply by the statutory deadline

Great Western Hospitals NHS Foundation Trust is taking partial action

Greater Manchester Mental Health NHS Foundation Trust did not reply by the statutory deadline

Guy's & St Thomas' NHS Foundation Trust did not reply by the statutory deadline

Hampshire Hospitals NHS Foundation Trust is taking action

Harrogate and District NHS Foundation Trust did not reply by the statutory deadline

Herefordshire and Worcestershire Health and Care NHS Trust has not demonstrated it is taking action

Hertfordshire Community NHS Trust did not reply by the statutory deadline

Hertfordshire Partnership University NHS Foundation Trust has not demonstrated it is taking action

Hillingdon Hospitals NHS Foundation Trust did not reply by the statutory deadline

Homerton University Hospital NHS Foundation Trust did not reply by the statutory deadline

Hounslow & Richmond Community Healthcare NHS Trust has not demonstrated it is taking action

Hull University Teaching Hospitals NHS Trust did not reply by the statutory deadline

Humber Teaching NHS Foundation Trust did not reply by the statutory deadline

Imperial College Healthcare NHS Trust did not reply by the statutory deadline

Isle of Wight NHS Trust is taking partial action

James Paget University Hospitals NHS Foundation Trust did not reply by the statutory deadline

Kent and Medway NHS and Social Care Partnership Trust did not reply by the statutory deadline

Kent Community Health NHS Foundation Trust is taking partial action

Kettering General Hospital NHS Foundation Trust did not reply by the statutory deadline

Kings College Hospital NHS Foundation Trust did not reply by the statutory deadline

Kingston Hospital NHS Foundation Trust did not reply by the statutory deadline

Lancashire & South Cumbria NHS Foundation Trust did not reply by the statutory deadline

Lancashire Teaching Hospitals NHS Foundation Trust has not demonstrated it is taking action

Leeds Community Healthcare NHS Trust did not reply by the statutory deadline

Leeds Teaching Hospitals NHS Trust has not demonstrated it is taking action

Leicestershire Partnership NHS Trust is taking partial action

Lewisham and Greenwich NHS Trust did not reply by the statutory deadline

Lincolnshire Community Health Services NHS Trust has not demonstrated it is taking action

Lincolnshire Partnership NHS Foundation Trust has not demonstrated it is taking action

Liverpool Heart and Chest Hospital NHS Foundation Trust has not demonstrated it is taking action

Liverpool University Hospitals NHS Foundation Trust has not demonstrated it is taking action

Liverpool Women's NHS Foundation Trust did not reply by the statutory deadline

London Ambulance Service NHS Trust is exempted from results

London North West University Healthcare NHS Trust did not reply by the statutory deadline

Maidstone and Tunbridge Wells NHS Trust did not reply by the statutory deadline

Manchester University NHS Foundation Trust did not reply by the statutory deadline

Medway NHS Foundation Trust did not reply by the statutory deadline

Mersey and West Lancashire Teaching Hospitals NHS Trust did not reply by the statutory deadline

Mersey Care NHS Foundation Trust has not demonstrated it is taking action

Mid and South Essex NHS Foundation Trust is taking partial action

Mid Cheshire Hospitals NHS Foundation Trust did not reply by the statutory deadline

Mid Yorkshire Hospitals NHS Trust did not reply by the statutory deadline

Midlands Partnership NHS Foundation Trust delivery failure

Milton Keynes University Hospital NHS Foundation Trust has not demonstrated it is taking action

Moorfields Eye Hospital NHS Foundation Trust did not reply by the statutory deadline

Newcastle Upon Tyne Hospitals NHS Foundation Trust is taking action

Norfolk and Norwich University Hospitals NHS Foundation Trust did not reply by the statutory deadline

Norfolk and Suffolk NHS Foundation Trust has not demonstrated it is taking action

Norfolk Community Health and Care Trust has not demonstrated it is taking action

North Bristol NHS Trust did not reply by the statutory deadline

North Cumbria Integrated Care NHS Foundation Trust has not demonstrated it is taking action

North East Ambulance Service NHS Foundation Trust has been exempted from results

North East London NHS Foundation Trust did not reply by the statutory deadline

North Middlesex University Hospital NHS Trust did not reply by the statutory deadline

North Staffordshire Combined Healthcare NHS Trust has not demonstrated it is taking action

North Tees and Hartlepool NHS Foundation Trust did not reply by the statutory deadline

North West Ambulance Service NHS Trust has been exempted from results

North West Anglia NHS Foundation Trust is taking partial action

Northampton General Hospital NHS Trust did not reply by the statutory deadline

Northamptonshire Healthcare NHS Foundation Trust is taking partial action

Northern Care Alliance NHS Foundation Trust is taking partial action

Northern Lincolnshire and Goole NHS Foundation Trust is taking action

Northumbria Healthcare NHS Foundation Trust has not demonstrated it is taking action

Nottingham University Hospitals NHS Trust did not reply by the statutory deadline

Nottinghamshire Healthcare NHS Trust has not demonstrated it is taking action

Oxford Health NHS Foundation Trust is taking partial action

Oxford University Hospitals NHS Foundation Trust did not reply by the statutory deadline

Oxleas NHS Foundation Trust is taking action

Pennine Care NHS Foundation Trust did not reply by the statutory deadline

Portsmouth Hospitals University NHS Trust did not reply by the statutory deadline

Princess Alexandra Hospital NHS Trust did not reply by the statutory deadline

Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust did not reply by the statutory deadline

Queen Victoria NHS Foundation Trust has not demonstrated it is taking action

Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust has not demonstrated it is taking action

Rotherham Doncaster and South Humber NHS Foundation Trust has not demonstrated it is taking action

Rotherham NHS Foundation Trust is taking partial action

Royal Berkshire NHS Foundation Trust did not reply by the statutory deadline

Royal Cornwall Hospitals NHS Trust did not reply by the statutory deadline

Royal Devon University Healthcare NHS Foundation Trust did not reply by the statutory deadline

Royal Free London NHS Foundation Trust delivery error

Royal Marsden NHS Foundation Trust has not demonstrated it is taking action

Royal National Orthopaedic Hospital NHS Trust has not demonstrated it is taking action

Royal Orthopaedic Hospital NHS Foundation Trust has not demonstrated it is taking action

Royal Papworth Hospital NHS Foundation Trust has not demonstrated it is taking action

Royal Surrey NHS Foundation Trust has not demonstrated it is taking action

Royal United Hospitals Bath NHS Foundation Trust did not reply by the statutory deadline

Royal Wolverhampton NHS Trust did not reply by the statutory deadline

Salisbury NHS Foundation Trust did not reply by the statutory deadline

Sandwell and West Birmingham Hospitals NHS Trust did not reply by the statutory deadline

Sheffield Children's NHS Foundation Trust is taking partial action

Sheffield Health and Social Care NHS Foundation Trust is taking partial action

Sheffield Teaching Hospitals NHS Foundation Trust did not reply by the statutory deadline

Sherwood Forest Hospitals NHS Foundation Trust did reply by the statutory deadline

Shrewsbury and Telford Hospital NHS Trust is not taking action

Shropshire Community Health NHS Trust is taking action

Solent NHS Trust has not demonstrated it is taking action

Somerset NHS Foundation Trust did not reply by the statutory deadline

South Central Ambulance Service NHS Foundation Trust has been exempted from results

South East Coast Ambulance Service NHS Foundation Trust has been exempted from results

South London and Maudsley NHS Foundation Trust did not reply by the statutory deadline

South Tees Hospitals NHS Foundation Trust is taking action

South Tyneside and Sunderland NHS Foundation Trust is taking action

South Warwickshire NHS Foundation Trust is taking partial action

South West London and St George's Mental Health NHS Trust did not reply by the statutory deadline

South West Yorkshire Partnership NHS Foundation Trust has not demonstrated it is taking action

South Western Ambulance Service NHS Foundation Trust has been exempted from results

Southern Health NHS Foundation Trust did not reply by the statutory deadline

Southport and Ormskirk Hospital NHS Trust did not reply by the statutory deadline

St George's University Hospitals NHS Foundation Trust is taking partial action

Stockport NHS Foundation Trust did not reply by the statutory deadline

Surrey and Borders Partnership NHS Foundation Trust did not reply by the statutory deadline

Surrey and Sussex Healthcare NHS Trust did not reply by the statutory deadline

Sussex Community NHS Foundation Trust did not reply by the statutory deadline

Sussex Partnership NHS Foundation Trust is taking action

Tameside and Glossop Integrated Care NHS Foundation Trust did not reply by the statutory deadline

Tavistock and Portman NHS Foundation Trust has not demonstrated it is taking action

Tees, Esk and Wear Valleys NHS Foundation Trust is taking action

Torbay and South Devon NHS Foundation Trust has not demonstrated it is taking action

United Lincolnshire Hospitals NHS Trust did not reply by the statutory deadline

University College London Hospitals NHS Foundation Trust did not reply by the statutory deadline

University Hospital Southampton NHS Foundation Trust is taking action

University Hospitals Birmingham NHS Foundation Trust did not reply by the statutory deadline

University Hospitals Bristol and Weston NHS Foundation Trust has not demonstrated it is taking action

University Hospitals Coventry and Warwickshire NHS Trust did not reply by the statutory deadline

University Hospitals Dorset NHS Foundation Trust did not reply by the statutory deadline

University Hospitals of Derby and Burton NHS Foundation Trust is taking partial action

University Hospitals of Leicester NHS Trust has not demonstrated it is taking action

University Hospitals of Morecambe Bay NHS Foundation Trust is taking partial action

University Hospitals of North Midlands NHS Trust did not reply by the statutory deadline

University Hospitals Plymouth NHS Trust is taking action

University Hospitals Sussex NHS Foundation Trust did not reply by the statutory deadline

Velindre NHS Trust has not demonstrated it is taking action

Walsall Healthcare NHS Trust is taking action

Walton Centre NHS Foundation Trust has not demonstrated it is taking action

Warrington and Halton Teaching Hospitals NHS Foundation Trust has not demonstrated it is taking action

Welsh Ambulance Services NHS Trust has been exempted from results

West Hertfordshire Teaching Hospitals NHS Trust has not demonstrated it is taking action

West London NHS Trust did not reply by the statutory deadline

West Midlands Ambulance Service University NHS Foundation Trust has been exempted from results

West Suffolk NHS Foundation Trust did not reply by the statutory deadline

Whittington Health NHS Trust has not demonstrated it is taking action

Wirral Community Health & Care NHS Foundation Trust did not reply by the statutory deadline

Wirral University Teaching Hospital NHS Foundation Trust did not reply by the statutory deadline

Worcestershire Acute Hospitals NHS Trust is taking partial action

Wrightington, Wigan and Leigh NHS Foundation Trust did not reply by the statutory deadline

Wye Valley NHS Trust is taking partial action

York and Scarborough Teaching Hospital NHS Foundation Trust did not reply by the statutory deadline

Yorkshire Ambulance Service NHS Trust has been exempted from results

Note: Ambulance Trust responses were not included in the tallies but we believe they should still have FASD training as many do for Autism and Learning Disabilities.

ADDRESSING THE UK DATA BLIND SPOT – UK NATIONAL LINKED DATABASE FOR PAE AND FASD

Preventing Harm from Prenatal Alcohol Exposure:
Addressing the UK data blind spot

What is the problem and how can we address this?

- **Landmark UK policy and guidance** has called for urgent action to increase prevention, identification, and support for those affected by prenatal alcohol exposure and fetal alcohol spectrum disorder (FASD).[1-3]
- A **paucity of national data** undermines the feasibility of achieving this.
- We can address this critical FASD 'data gap' by establishing the **first UK National Linked Database for prenatal alcohol exposure and FASD.**
- This **essential, world-leading resource** would securely bring together de-identified FASD assessment records from NHS and private health settings that have not previously been available for research.
- **Clinical records** will be linked to **health, social care, economic and criminal justice data** - **harnessing the rich data infrastructure** available in the UK.
- **Our extensive consultations with public and professional stakeholders (including those living with FASD)** have demonstrated **strong support** for the creation of a UK national FASD database, **confirmed the feasibility** of establishing this resource, and has **identified Trusted Research Environments to securely house this data**.[4,5]
- **We are seeking follow-on funding to make this critical resource a reality** and would welcome contributions from the UK Government towards this – given the level of unmet need in our population, and the **strong alignment of our objectives with contemporary data transformation and FASD policies**.
- **A UK national FASD database would transform our understanding of this prevalent, yet poorly understood condition** – offering crucial insights into clinical profiles, opportunity for prevention, and interventions to improve outcomes, amounting to significant societal cost savings and vast improvements in outcomes for those living with FASD.

A visual summary of the UK National Database for FASD (Nat-FASD) and further supporting evidence is provided overleaf.

We thank you for consideration of this supplemental evidence for the Health and Social Care Committee major inquiry on the prevention of alcohol-related harm.

Dr Cheryl McQuire*
Research Fellow in Public Health Evaluation
Email: cheryl.mcquire@bristol.ac.uk
Population Health Sciences | Bristol Medical School | University of Bristol
Room 4.04, Canynge Hall | 39 Whatley Road | Bristol | BS8 2PS. Twitter/X: @cheryl_mcquire

*on behalf of the UK National FASD Database study team: Dr Cheryl McQuire, Amy Dillon, University of Bristol; Prof Raja Mukherjee, Surrey and Borders Partnership NHS Foundation Trust; Prof Penny Cook, University of Salford; Sandra Butcher, National Organisation for FASD; Andy Boyd, Director, UK Longitudinal Linkage Collaboration; Beverley Samways, University of Bristol; Dr Sarah Harding, University of Bristol

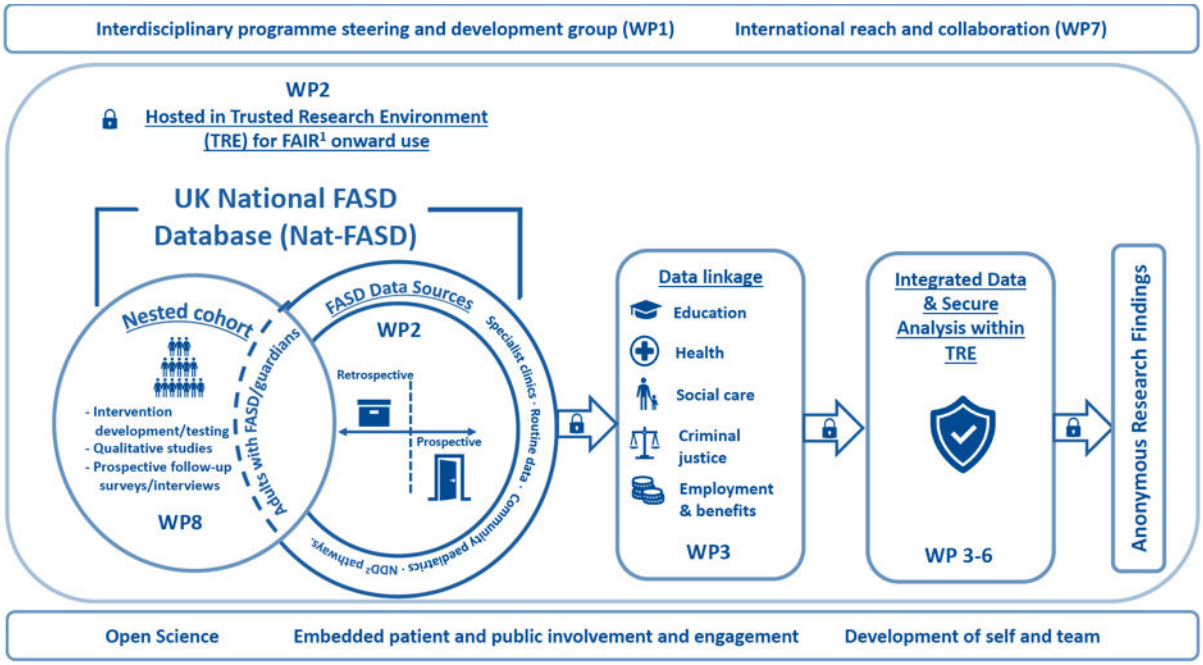


Figure 1: Visual summary of the planned UK National FASD Database (Nat-FASD); Blue boxes represent work packages (WPs), orange boxes represent overarching principles [1] FAIR principles for scientific data management and stewardship[6]; [b] NDD=neurodevelopmental disorder.

Further supporting evidence

- The UK has the 4th highest rate of prenatal alcohol use globally.[7]
- Prenatal alcohol exposure can lead to miscarriage, preterm birth, and lifelong neurodevelopmental conditions known as fetal alcohol spectrum disorder (FASD).[8]
- 2% - 4% of children in the UK general population are thought to have FASD,[9-11] rising to nearly 1 in 3 among Looked After Children.[12]
- The costs of FASD are enormous - exceeding costs for autism by 26% - due to high rates of health care needs, involvement with the criminal justice system and lost productivity.[13]
- Publication of the National Institute for Health and Care Excellence (NICE) Quality Standard for FASD in 2022 sets the strongest precedent yet for improved prevention, assessment, and support for prenatal alcohol exposure and FASD.[2]
- However, reliable and accessible data on FASD is not available. This makes it difficult to achieve important FASD research, policy, and healthcare goals.

The solution

- The UK government has called for a transformation in the way people's information (data) is used to improve health.
- An important step towards addressing the FASD 'data gap' will be to produce the first UK National Linked Database for FASD. This would bring together de-identified FASD assessment records from NHS and private health settings that have not previously been available for research. These records would be stored in a trusted research environment, enabling researchers to use the data in way that protects people's privacy. FASD records could then be linked to other population records including health, education, employment, crime, and social care.
- It would provide crucial insights into the characteristics and needs of people living with FASD, impacts and costs of FASD in the UK, and identify opportunities for improving outcomes.

References:

1. Department of Health and Social Care. Fetal alcohol spectrum disorder: health needs assessment. 2021.
2. National Institute for Health and Care Excellence. Fetal alcohol spectrum disorder. Quality standard [QS204]. 2022.
3. Public Health England (PHE). Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy. 2020.

4. Harding S, Samways, B., Dillon, A., Butcher, S., Boyd, A., Mukherjee, R., Cook, P., McQuire, C. Addressing the fetal alcohol spectrum disorder (FASD) 'data gap': Multi-method and multi-disciplinary public engagement to ascertain the acceptability and feasibility of establishing the first UK National linked database for FASD. International Journal of Population Data Science. 2023;8(2).
5. McQuire C. Addressing the fetal alcohol spectrum disorder (FASD) 'data gap'. In. JGI Seed Corn Funding Project Blog 2022-2023: Jean Golding Institute, University of Bristol; 2023.
6. Wilkinson MD, Dumontier M, Aalbersberg IJ, et al. The FAIR Guiding Principles for scientific data management and stewardship. Scientific Data. 2016;3(1):160018.
7. Popova S, Lange S, Probst C, Gmel G, Rehm J. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. Lancet Glob Health. 2017;5(3):e290-e299.
8. Popova S, Charness ME, Burd L, et al. Fetal alcohol spectrum disorders. Nature Reviews Disease Primers. 2023;9(1):11.
9. McCarthy R, Mukherjee RAS, Fleming KM, et al. Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study. Alcoholism, clinical and experimental research. 2021;45(11):2271-2281.
10. Lange S, Probst C, Gmel G, Rehm J, Burd L, Popova S. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis. JAMA Pediatrics. 2017;171(10):948-956.
11. McQuire C, Mukherjee R, Hurt L, et al. Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study. Prev Med. 2019;118:344-351.
12. Gregory G, Reddy V, Young C. Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis. Adoption & Fostering. 2015;39(3):225-234.
13. Greenmyer JR, Klug MG, Kambeitz C, Popova S, Burd L. A Multicountry Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults. Journal of Addiction Medicine. 2018;12(6).