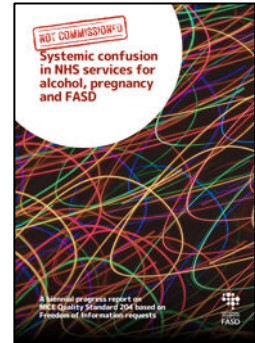


## SUMMARY

*Not Commissioned: Systemic confusion in NHS services for alcohol, pregnancy, & FASD*  
A biennial progress report on NICE Quality Standard 204 based on Freedom of Information requests <https://nationalfasd.org.uk/not-commissioned-report/>



- 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 the 2022 NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder (FASD). NICE QS 204 is in effect in England and Wales and calls for improvements in care regarding discussions about risks of alcohol in pregnancy during antenatal visits and recognition, diagnosis and support of those with FASD.
- While there are pockets of hope and encouraging progress, more broadly there is systemic confusion and a lack of coordination and commissioning across the NHS.
- Nearly 53% of Integrated Care Boards (ICBs) and 56% of NHS Trusts (not including the 11 specialist ambulance trusts) that replied by the statutory deadline to National FASD's Freedom of Information requests are not taking action to meet the needs of this vulnerable population with FASD and to prevent alcohol-exposed pregnancies. In Wales all the health boards that responded are taking at least partial action.
- There are unclear lines of responsibility between ICBs/ Health Boards and Trusts, as well as within Trusts between different services.
- The vast majority of English ICBs that replied by the statutory 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%). Responses indicate the rest of the NICE QS 204 suggestions for commissioners are not being followed.
- There is a nearly universal failure to track improvements in services over time using NICE indicators.
- Training across the workforce as called for by NICE is not happening in many areas.
- Local pathways are unclear and under resourced. Many responses indicate that local diagnosis is not available.
- Appendices include the questions asked and the responses received and link to the full responses to help spur creative thinking from leaders in different areas.

National FASD calls for strong leadership from Parliament, Government and national health bodies to operationalise the NICE Quality Standard, including:

- Meetings between policy makers and people with FASD and their families.
- English and Welsh Green Papers looking into FASD Prevention and Response.
- 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.
- Support from NHS England for an ongoing audit of progress following NICE Quality Standard 204,
- NHS England and NHS Wales should give clear guidance about the need to commission services outlined in NICE QS 204.
- 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..
- Recently introduced SNOMED CT codes for FASD should be promoted by the Chief Medical Officers.
- Digital health records for maternity services need to be updated to include mandatory, consistent coding and prompts for discussing and recording dose, pattern and timing of alcohol-exposed pregnancies.
- The risks of alcohol in pregnancy should be promoted at least on scale with smoking in pregnancy.
- Steps need to be taken to increase local and regional diagnostic capacity on a Hub and Spoke model.
- Each area needs to have a plan in place for post-diagnostic support, and 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.
- Any NHS programme for people Autism and Learning Disabilities or for those with neurodevelopmental conditions must take into account SIGN 156, the DHSC FASD Health Needs Assessment and NICE QS 204.
- There is a need for national level guidance, oversight and funding for FASD training across health and social care sectors.