NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

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| Quality standard topic: Fetal alcohol spectrum disorder  Output: Prioritised quality improvement areas for development.  Date of Quality Standards Advisory Committee meeting: 10 December 2019 |

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for Fetal Alcohol Spectrum Disorder (FASD). It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development sources below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development sources referenced in this briefing paper are:

[Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html). Scottish Intercollegiate Guidelines Network (SIGN) 156. Published January 2019.

[Antenatal care for uncomplicated pregnancies](https://www.nice.org.uk/guidance/cg62). NICE guideline CG62. Published March 2008. A full update of this guideline is in progress, with publication expected April 2021.

1. Overview
   1. Focus of quality standard

This quality standard will cover assessment and diagnosis of people affected by FASD. It will also cover alcohol consumption during pregnancy.

* 1. Description

FASD is an umbrella term used to describe a wide range of disorders associated with alcohol consumption in pregnancy. Alcohol consumption in pregnancy has the potential to affect the fetus in different ways and result in life-long physical, behavioural and cognitive difficulties. Different terms and definitions have been used to describe the diverse presentations of children prenatally exposed to alcohol. Fetal alcohol syndrome (FAS) was first used in 1973 and has specific diagnostic criteria including evidence of prenatal alcohol exposure, central nervous system abnormalities, facial abnormalities and growth impairment. Other terms used cover presentations of some, but not all, of the features of FAS. These include:

* fetal alcohol effects
* alcohol-related birth defects
* alcohol-related neurodevelopment disorder
* partial fetal alcohol syndrome

neurodevelopmental disorder – prenatal alcohol exposure

These wider patterns of effects, along with FAS, are all captured by the term FASD.

* 1. Incidence and prevalence

The actual prevalence of FASD in the UK is unknown, and there is no reliable evidence on the incidence of FASD. An All Party Parliamentary Group for FASD[[1]](#footnote-1) and the BMA[[2]](#footnote-2) have recommended a UK wide prevalence study to ascertain the number of people with FASD living in the UK.

Estimates of the prevalence of FASD have been produced, though. Popova et al[[3]](#footnote-3) produced global and national figures based on a meta-analysis of 24 studies. They estimated a global prevalence of FASD of 7.7 per 1,000 population and a UK prevalence of 32.4 per 1,000 population.

McGuire et al[[4]](#footnote-4) used a different method to estimate the screening prevalence of FASD. They took detailed and complex data from a longitudinal study in the Bristol area. This data covered pregnant women with delivery dates between 1991 and 1992, and their children up until they were 15 years old. An algorithm was developed which took account of the presence of reduced growth, behaviour, mental and/or motor development to indicate if a child had been adversely affected by the mother having drunk alcohol in pregnancy. Prevalence estimates calculated ranged from 6.0% to 17.0% depending on strategy used to manage missing data. It should be noted that screening algorithms are not equivalent to a formal diagnosis of FASD. FASD diagnosis requires input from a multidisciplinary team, with an opportunity to interact with the child and their caregivers, to allow a thorough analysis of a child's developmental profile and consider differential diagnoses. The estimates represent a screening prevalence; that is the proportion of participants who met criteria for any condition within the FASD continuum, based on an algorithm applied to data.

The Chief Medical Officers’ [Low Risk Drinking Guidelines](https://www.gov.uk/government/publications/alcohol-consumption-advice-on-low-risk-drinking) say that the safest approach for women who are pregnant is not to drink alcohol to minimise risks to a baby. However, estimates show that a significant proportion of women consume alcohol during pregnancy. Popova et al3 estimated that 41.3% of women in the UK consume alcohol during pregnancy. This estimate is based on systematic review of quantitative studies that reported the prevalence in the general population of alcohol use during pregnancy. A similar proportion was reported by the 2010 Infant Feeding Survey[[5]](#footnote-5). This survey found that 41% of mothers in England drank alcohol during pregnancy. More recent information is available from the Office for National Statistics adult drinking habit data[[6]](#footnote-6). This data is sourced from the Opinion and Lifestyle survey and is based on responses of around 7,100 people to questions about drinking habits in the previous week. Results for 2017 show that approximately one in 10 pregnant women (11.3%) in Great Britain reported drinking some alcohol in the last week.

* 1. Current service delivery and management

The diagnosis and management of FASD requires a multidisciplinary approach involving a wide range of healthcare professionals such as paediatricians, obstetricians, speech and language therapists, occupational therapists, psychologists, GPs, neurologists, psychiatrists, clinical geneticists, health visitors and midwives. It also includes individuals in the fields of education and social care as well as families, carers and advocates.

Diagnosis of FASD is difficult2. Damage to the brain and developmental delay may not be obvious in very young children, there are genetic and malformation syndromes that have similar characteristics to FASD, and children affected by FASD may have another genetic syndrome as a comorbidity. A complete maternal history is an important component in FASD diagnosis. Appendix 1 shows the diagnostic algorithm for FASD.

Diagnosis at the earliest possible stage allows for early intervention and treatment programmes and a better overall outcome for an individual with FASD. Better understanding of the condition can help parents and professionals cope more appropriately with the child’s difficulties. This extends beyond healthcare, for example through development of targeted educational and social support programmes.

FASD is a lifelong condition. If difficulties are not anticipated and understood, educational opportunities will not be optimised and some affected children and young people will have poor educational attainment, develop mental health problems, and have a higher risk of becoming addicted to alcohol and other drugs. These children and young people are also more likely to become involved in criminal activity and die prematurely from violence, accident or suicide.

There is a lack of services specifically for FASD. The All Party Parliamentary Group report1 notes that there is only one FASD clinic in the UK, and that some other medics are attempting to run FASD clinics within their normal community clinical schedules but this is under-funded and unrecognised. The Inquiry also heard post-diagnostic support from statutory services for individuals and their families described as negligible, inconsistent and often inappropriate.

* 1. Resource impact

NICE has not produced a resource impact report for FASD as it has not developed a guideline on FASD. Resource implications for Scotland are identified by SIGN in [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html). Additional resources are expected to be required as a result of the recommendations. These resource impacts are described for Scotland, but not quantified. Staff costs are likely to be the main resource impact, associated with assessment and follow up of individuals who have (or are at risk of) an FASD diagnosis. Depending on the social care needs of individuals, there may also be additional staff costs for local authority social care partners and third sector organisations.

A BMA report2 says that international data indicate FASD has a significant financial burden. Based on data from the US, the annual cost of FASD in the UK is estimated to be over £2 billion.

1. Summary of suggestions
   1. Responses

A 5-week topic engagement exercise ran from 02/09/19 to 08/10/19 after which selected key stakeholders were followed up. In total 21 registered stakeholders responded. We also received comments from 8 specialist committee members. The responses have been merged and summarised in table 1 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

The FASD UK Alliance supplied a report summarising a survey of over 320 families affected by FASD to inform the topic engagement process (see appendix 3).

A number of stakeholders made additional comments. These related to the source material referenced in the topic overview document, and disclosing links with the alcohol and tobacco industries.

### Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders |
| --- | --- |
| Raising awareness | CoramBAAF, DHSC, FASD GM, FASDNUK, NA, NH, RCPCH, SCM1, SCM5, SCM8, TACT, UK National FASD clinic |
| Identification of children and young people at risk of FASD | BPAS, CoramBAAF, FASDA SE, GMHSCP, NH, NOFAS, PHE, RCPCH, SCM2, SCM3, SCM4, SCM5, SCM6, SCM7, SCM8 UKNSC |
| Diagnosis and assessment | AUK, BMA, BPAS, CoramBAAF, DHSC, EAST Herts FSN, ELCS, FASDA SE, FASD GM, FASDNUK, GMHSCP, NOFAS, NA, RCN, RCPCH, RCSLT, SCM1, SCM2, SCM3, SCM4, SCM5, SCM6, SCM7, SCM8, TACT |
| Management and follow up | AUK, BMA, CoramBAAF, EAST Herts FSN, ELCS, FASD GM, FASDNUK, NA, RCN, SCM1, SCM5 |
| Additional areas |  |
| * Training | AUK, DHSC, EAST Herts FSN, FASDA SE, FASD GM, FASDNUK, GMHSCP, NOFAS, NA, NH, SCM1, SCM6, SCM7, SCM8, TACT |
| * Need for national FASD strategy | AUK |
| * Recognition of FASD as neurodevelopment disorder / lifelong disability | AUK, EAST Herts FSN, FASDA SE, FASDNUK, NOFAS, SCM1, SCM6, |
| * Public health policy / regulations | ELCS |
| * New / amended guidelines | BMA, FASDNUK |
| * Meconium testing of newborns | SCM6 |
| * Better parenting interventions | SCM5 |
| * Identification of people at risk of alcohol ‘harm’ | DHSC |
| * Long Acting Reversible Contraception | PHE, SCM7 |
| * Coordination and continuity of care | AUK, ELCS, FASD GM, PHE |
| * Annual audit of maternity notes and national recording of FASD data | DHSC, NH |
| Abbreviations:  AUK: Adoption UK  BMA: British Medical Association  BPAS: British Pregnancy Advisory Service  CoramBAAF  DHSC: Department of Health and Social Care  EAST Herts FSN: East Herts and Area FASD Support Network  ELCS: Evelina London Community Services  FASDA SE: FASD Awareness South East  FASD GM: FASD Greater Manchester  FASDNUK: FASD Network UK  GMHSCP: Greater Manchester Health and Social Care Partnership  NOFAS: National Organisation for Foetal Alcohol Syndrome-UK  NA: Neurological Alliance  NH: Northumbria Healthcare Foundation NHS Trust  PHE: Public Health England  RCN: Royal College of Nursing  RCPCH: Royal College of Paediatrics and Child Health  RCSLT: Royal College of Speech and Language Therapists  TACT: (fostering charity)  UK National FASD Clinic  UK NSC: UK National Screening Committee  SCM1 to SCM 8, Specialist Committee Member | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 97 papers were identified for FASD. In addition, 154 papers were suggested by stakeholders at topic engagement and 22 papers internally at project scoping.

Of these papers, 13 have been included in this report and are included in the current practice sections where relevant. Appendix 5 outlines the search process.

1. Suggested improvement areas
   1. Raising awareness
      1. Summary of suggestions

Stakeholders suggested prevention of FASD through education and raising awareness of the risks of drinking alcohol in pregnancy. This could be achieved in different ways: by supporting local areas to undertake awareness campaigns; healthcare professionals providing consistent advice and discussing the risks of alcohol use; maternity professionals working with alcohol partnership groups; and primary care services and gynaecology clinics providing information on FASD and prenatal alcohol consumption. Different target populations were suggested including all women of childbearing age, those wanting to conceive and those in all stages of pregnancy. Comments state that many women are not aware of risks of alcohol consumption in pregnancy; information is often not provided; and when provided it can be ambiguous, inconsistent and incorrect.

* + 1. Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. The recommendations are presented in full after table 2 to help inform the committee’s discussion.

### Table 2 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Raising awareness | **Maternal alcohol history**  SIGN 156 recommendation 2.1 (page 11)  **Antenatal information**  NICE CG62 recommendation 1.1.1 |

### Maternal alcohol history

SIGN 156 Recommendation 2.1 (page 11)

All pregnant and postpartum women should be screened for alcohol use with validated measurement tools by service providers who have received appropriate training in their use. All women should be advised not to consume alcohol in pregnancy; additionally those women drinking above the low-risk guideline for the general population should be offered early, brief interventions (ie counselling and/or other services).

### Antenatal information

NICE CG62 Recommendation 1.1.1

Antenatal information should be given to pregnant women according to the following schedule.

* At the first contact with a healthcare professional:
  + - folic acid supplementation
    - food hygiene, including how to reduce the risk of a food‑acquired infection
    - lifestyle advice, including smoking cessation, and the implications of recreational drug use and alcohol consumption in pregnancy
    - all antenatal screening, including screening for haemoglobinopathies, the anomaly scan and screening for Down's syndrome, as well as risks and benefits of the screening tests.
    1. Current UK practice

The Infant Feeding Survey 2010[[7]](#footnote-7) found that 29% of women in England who drank before pregnancy had received no information about drinking in pregnancy. For those who did receive information, the type of information varied: 61% of women had been given general information about the effects of drinking alcohol on the baby; 36% had information on limiting the amount of alcohol they drank; but only 28% had been given information on stopping drinking alcohol completely.

A study of midwives on giving advice about alcohol was undertaken in East Anglia[[8]](#footnote-8). In 2011, a postal survey was sent to 1,862 midwives in 13 NHS trusts. Of 624 respondents, 29% of midwives routinely provided information on alcohol during pregnancy. In terms of advice, 93% of midwives preferred to give the advice that pregnant women should consider not drinking alcohol at all.

In 2017, online and mobile polling of 150 GPs in England was undertaken for the National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK)[[9]](#footnote-9). Of GPs who responded, 75% said they had literature and posters in their offices specifically about the risks of alcohol and pregnancy. 95% said they think GPs should ask all women who are pregnant, or planning to become pregnant, about their alcohol use and not just those who are at risk.

Mukherjee et al[[10]](#footnote-10) undertook a mixed methodology study using a questionnaire and focus group sessions to assess the level of knowledge about FASD in the UK general population. A total of 674 people responded to the questionnaire. 60% of respondents were aware of the UK government guidance on drinking alcohol in pregnancy, but most considered the guidance not clear or understandable. The results showed variation in the level of alcohol consumption thought to cause risk to the fetus.

The All Party Parliamentary Group for FASD report[[11]](#footnote-11) states that one of the key means through which the drinks industry raises awareness about the harm of alcohol consumption for fetus is through bottle labelling and that 91% of alcoholic drinks bottles/cans in the UK carry a warning about drinking during pregnancy.

* + 1. Resource impact

No resource impact is expected to result from giving information about the dangers of alcohol use or recording alcohol use during pregnancy.

* 1. Identification of children and young people at risk of FASD
     1. Summary of suggestions

Assessing alcohol consumption during pregnancy was suggested by stakeholders to identify children at risk of FASD. Comments suggested different ways of assessing alcohol use, including universal screening of pregnant women; assessing alcohol use of pregnant women at different points in time (such as at the antenatal booking appointment, throughout pregnancy, neonatal and postnatal check); and assessing different populations (such as pregnant women, all women planning pregnancy, women at risk of alcohol exposed pregnancy). As well as identifying those at risk of FASD, assessment of alcohol consumption gives an opportunity to provide advice on risks and to offer support. The UK Chief Medical Officers’ (CMO) [low risk drinking guidelines](https://www.gov.uk/government/publications/alcohol-consumption-advice-on-low-risk-drinking) were flagged by some stakeholders as being important to communicate.

Some stakeholders emphasised the importance of recording information on alcohol consumption in records for the child and for the parent, and also on ensuring this information is shared between professionals (such as between the midwife, health visitor and GP) and across services (such as between primary care secondary care and social care). Use of tools to assess and record alcohol use was suggested by some stakeholders.

Some comments were specifically about screening and the role of the UK National Screening Committee (UK NSC). One stakeholder said that universal screening for maternal alcohol consumption in SIGN 156 has not been subject to ethical assessments and could adversely affect informed consent and the privacy interests of women. They added that any recommendation related to population screening during pregnancy falls under the remit on the UK NSC. The UK NSC also stated that recommendations on population screening during pregnancy would fall under their remit.

* + 1. Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 3 to help inform the committee’s discussion.

### Table 3 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Identification of children and young people at risk of FASD | **Maternal alcohol history**  SIGN 156 Recommendation 2.1 (page 11)  **Assessing likely prenatal alcohol exposure**  SIGN 156 Recommendation 2.1.1 (page 11)  **Recording the pattern of alcohol consumption**  SIGN 156 Recommendation 2.1.2 (page 12)  **Screening for prenatal alcohol exposure**  SIGN 156 Recommendation 2.1.3 (page 13) |

### Maternal alcohol history

SIGN 156 Recommendation 2.1 (page 11)

All pregnant and postpartum women should be screened for alcohol use with validated measurement tools by service providers who have received appropriate training in their use. All women should be advised not to consume alcohol in pregnancy; additionally those women drinking above the low-risk guideline for the general population should be offered early, brief interventions (ie counselling and/or other services).

### Assessing likely prenatal alcohol exposure

SIGN 156 Recommendation 2.1.1 (page 11)

Confirmation of PAE requires documentation that the biological mother consumed alcohol during the index pregnancy based on:

* reliable clinical observation
* self report or reports by a reliable source
* medical records documenting positive blood alcohol concentrations, or
* alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy.

### Recording the pattern of alcohol consumption

SIGN 156 Recommendation 2.1.2 (page 12)

The number of type(s) of alcoholic beverages consumed (dose), the pattern of drinking and the frequency of drinking in pregnancy should all be documented.

Sources for confirmed prenatal alcohol history must be reliable and devoid of any conflict of interest. Unsubstantiated information, lifestyle alone, other drug use or history of alcohol exposure in previous pregnancies cannot, in isolation, confirm alcohol consumption in the index pregnancy. However, co-occurring disorders, significant psychosocial stressors and prenatal exposure to other substances (eg smoking, licit or illicit drugs) in the index and previous pregnancies should still be recorded, based on the known interactions of these substances and their effects on pregnancy outcomes for both the mother and her offspring.

### Screening for prenatal alcohol exposure

SIGN 156 Recommendation 2.1.3 (page 13)

Use of the T-ACE, TWEAK or AUDIT-C tools in screening women in the antenatal period for alcohol consumption should be considered.

Associated use of particular biomarkers, such as CDT and PEth, alongside brief screening questionnaires, should be considered.

* + 1. Current UK practice

An online survey of health care professionals’ perceived knowledge, attitudes, and clinical practices relating to alcohol in pregnancy and FASD was undertaken in the UK by Howlett et al[[12]](#footnote-12). The survey was undertaken between 2015 and 2016, and 250 responses were received from midwives, health visitors, obstetricians, paediatricians, and general practitioners. The survey found that most healthcare professionals asked patients about alcohol use in pregnancy (91% of midwives, 93% of health visitors, 75% of obstetricians, and 54% of GPs), with the most common approach being detailed questioning. Most midwifes (68%) had referred someone for alcohol use in pregnancy, most often to an alcohol specialist nurse or an obstetrician. The levels of drinking that led to a referral varied: for example 43% of midwives said they would refer for any reported alcohol consumption, 11% would refer if someone reported drinking more than 14 units per week and 15% only if a patient was visibly drunk at an appointment.

A mixed-methods design (survey, focus groups and interviews) to explore barriers and midwives’ beliefs about addressing alcohol during antenatal care with pregnant women was conducted by Scöhlin et al[[13]](#footnote-13). A total of 842 midwifes in the UK responded to the survey, 85% of whom were from England. The survey showed that 402 midwives (57%) in England were aware of the CMO guidelines. Of the 402 aware of the guidelines, 361 (90%) were aware that the content says to avoid alcohol completely during pregnancy. It also found that 97% of midwives in the UK ‘always’ or ‘usually’ advised women to abstain at the booking appointment, but this dropped to 38% at other appointments. Most midwives (70%) used no specific screening tool, many focused on ‘open conversations’ that were non-judgemental to encourage disclosure.

A study of midwives on giving advice about alcohol was undertaken in East Anglia[[14]](#footnote-14). In 2011, a postal survey was sent to 1,862 midwives in 13 NHS trusts. Of 624 respondents, 60% of midwives routinely asked women about antenatal alcohol use.

Public Health England have analysed twelve months’ data for pregnancy booking in 2017 from the Maternity Services Dataset[[15]](#footnote-15). Drinking status was recorded as ‘known’ for 56.9% of women (379,600 women). Of those, 97.1% reported drinking less than 1 unit of alcohol per week. The report says this information may not be accurate as it is a self-reported measure. By way of contrast, 87.8% of records have smoking status recorded. It should be noted that the Maternity Services Data Set is a maturing, national level dataset. As such it does not yet cover all deliveries in England. In 2017/18 the dataset recorded 78% of the deliveries recorded in Hospital Episodes Statistics.

A survey of 150 GPs by NOFAS-UK[[16]](#footnote-16) found that most GPs record information on patient records if is known that a patient drank during pregnancy. 71% of GPs said they would typically indicate somehow in the mother's or the child's records that the child should be assessed for cognitive function at a later point. However, 15% of GPs said they would not, and 14% said they didn’t know or preferred not to say.

* + 1. Resource impact

No resource impact is expected to result from giving information about the dangers of alcohol use or recording alcohol use during pregnancy.

* 1. Diagnosis and assessment
     1. Summary of suggestions

Access to diagnostic services and diagnostic pathways were suggested as priority areas. Stakeholders described diagnosis as the key to understanding the condition, accessing appropriate treatment and getting support. Current access to diagnostic services was described as difficult and inequitable and improved commissioning and resourcing of diagnostic and assessment services was suggested.

Some comments identified assessment for specific groups such as looked after children, adopted children, children entering the care system, children without sentinel features and those at risk of neurodevelopmental disorder. Other comments identified specific aspects that assessment should include such as balance; hearing, listening difficulties; neurodevelopmental assessment; educational & behavioural difficulties; and speech, language and communication.

The need for individualised support was highlighted by some stakeholders. The diagnosis and assessment process can cause anxiety, stigma and affect family functioning.

* + 1. Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 4 to help inform the committee’s discussion.

### Table 4 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Diagnosis and assessment | **Referral**  SIGN 156 Recommendation 2.1.4 (page 14)  **Diagnostic criteria: FASD**  SIGN 156 Recommendation 3.1.1 (page 15)  **The use of FASD as a diagnostic term**  SIGN 156 Recommendation 3.1.3 (page 17)  **Medical assessment**  SIGN 156 Recommendation 3.2 (page 17)  **Neurodevelopmental assessment: Areas of assessment**  SIGN 156 Recommendation 3.4.1 (page 21)  **Special considerations in the assessment of infants, children and young people**  SIGN 156 Recommendation 3.5 (page 23)  **Individualising the assessment**  SIGN 156 Recommendation 3.6.1 (page 24)  **The assessment team**  SIGN 156 Recommendation 3.7 (page 25) |

### Referral

SIGN 156 Recommendation 2.1.4 (page 14)

Referral of individuals for consideration of PAE as a cause of possible neurodevelopmental disorder should be made sensitively and only when there is evidence of significant physical, developmental or behavioural concerns and probable PAE.

### Diagnostic criteria: FASD

SIGN 156 Recommendation 3.1.1 (page 15)

A diagnosis of FASD with sentinel facial features\* may be made if an individual meets the following criteria:

* simultaneous presentation of the three sentinel facial features (short palpebral fissures, smooth philtrum and thin upper lip); AND
* prenatal alcohol exposure confirmed or unknown; AND
* evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment or, in infants and young children, presence of microcephaly.

A descriptor of FASD without sentinel facial features† may be used if an individual meets the following criteria:

* confirmation of prenatal alcohol exposure; AND
* evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment.

For both diagnoses:

* Contribution of genetic factors should be considered in all cases and referral may be indicated in atypical cases or where PAE is uncertain.
* Growth impairment and other birth defects and/or health issues should be documented if present.
* Hereditary, prenatal and postnatal factors that may influence developmental outcome should be recorded.

The diagnostic/descriptive criteria for FASD are the same for adults as for younger individuals

### The use of FASD as a diagnostic term

SIGN 156 Recommendation 3.1.3 (page 17)

FASD should now be used as a diagnostic/descriptor term when prenatal alcohol exposure is considered to be a significant contributor to observed deficits that cannot be fully explained by other aetiologies. Because the observed deficits are recognised as being multifactorial in origin, all other known relevant contributors (for example trauma or known genetic anomalies) should be documented with the FASD diagnosis/descriptor as they have significant impact on the functional and neurological challenges of the affected individuals.

### Medical assessment

SIGN 156 Recommendation 3.2 (page 17)

The diagnostic process should include a family, social and medical history as well as complete physical examination.

### Neurodevelopmental assessment: Areas of assessment

SIGN 156 Recommendation 3.4.1 (page 21)

A diagnosis/descriptor of FASD is made only when there is evidence of pervasive and long-standing brain dysfunction, which is defined by severe impairment (a global score or a major subdomain score on a standardised neurodevelopmental measure that is ≥2 SDs below the mean, with appropriate allowance for test error) in three of more of the following neurodevelopmental areas of assessment:

* motor skills
* neuroanatomy/neurophysiology
* cognition
* language
* academic achievement
* memory
* attention
* executive function, including impulse control and hyperactivity
* affect regulation, and
* adaptive behaviour, social skills or social communication

### Special considerations in the assessment of infants, children and young people

SIGN 156 Recommendation 3.5 (page 23)

Infants and young children with confirmed prenatal alcohol exposure, but who do not meet the criteria for FASD should be designated as ‘at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure’. Those with all three facial features, but no microcephaly, should be referred to a clinical geneticist.

A neurodevelopmental assessment is recommended for all children with confirmed prenatal alcohol exposure and/or all three facial features in whom there are clinical concerns.

### Individualising the assessment

SIGN 156 Recommendation 3.6.1 (page 24)

The length and structure of the assessment must accommodate the needs and capacity of the individual being assessed. It is important to recognise, for example, if the individual gets frustrated or tires easily; situational factors could invalidate the assessment.

### The assessment team

SIGN 156 Recommendation 3.7 (page 25)

Team members across the lifespan are:

* neonatologist/paediatrician/physician with competency in assessment of FASD
* child development specialists with the skillset to conduct physical and functional assessments (eg speech and language therapist, occupational therapist, clinical psychologist, educational psychologist).

Further individuals who can provide valuable input into the diagnostic process may include parents and carers, advocates, childcare workers, clinical geneticists, cultural interpreters, family therapists, general practitioners, learning support, mental health professionals, mentors, nurses (eg school, learning disability, etc), neuropsychologists, probation officers, psychiatrists, social workers, substance misuse service staff, teachers and vocational counsellors.

* + 1. Current UK practice

There is little quantitative information on current practice. The BMA report [Alcohol and pregnancy: Preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy) describes the current situation by saying there is no clear pathway in the UK for the referral of individuals with suspected FASD to allow a complete diagnostic evaluation. Consequently, there is inconsistency in where individuals with suspected FASD are referred. The report does recognise that there is a specialist national clinic, and some individual clinicians with an interest in FASD, but there is no specific commissioning of services for the diagnosis and management of FASD. The national clinic for FASD relies on individual funding requests.

NOFAS-UK[[17]](#footnote-17) published a report based on Freedom of Information requests sent to NHS Trusts, CCGs and other bodies in the UK in 2018. The report provides information on services commissioned and provided for FASD. Of 166 CCGs in England that responded, none have a policy for commissioning services specifically for FASD. The report identified that a small proportion of CCGs said that where diagnoses are provided, it is through general services or individual funding requests to visit to clinics such as the National FASD Clinic.

* + 1. Resource impact

If referrals into the specialist clinic increase as a result of the quality standard, then that could have a significant resource impact. This would depend on the number of referrals and current activity.

* 1. Management and follow up
     1. Summary of suggestions

Stakeholders suggested that a pathway or framework of care, support and treatment following diagnosis is needed. This would support professionals and ensure positive outcomes for those affected by FASD. Effective clinical management requires postnatal interventions and the cooperation between a wide range of healthcare professionals. Currently there is no pathway or framework, so many people do not receive ongoing support or are referred to services which are unable to provide appropriate help. Stakeholders described how people affected by FASD are often unable to access support and interventions following diagnosis. This affects physical and mental health, education, social inclusion and equality.

* + 1. Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 5 to help inform the committee’s discussion.

### Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Management and follow up | **Making the assessment meaningful**  SIGN 156 recommendation 3.6.2 (page 24)  **Communicating the results of assessment**  SIGN 156 recommendation 4.1.1 (page 27)  **Follow up**  SIGN 156 recommendation 4.1.2 (pages 27-28) |

### Making the assessment meaningful

SIGN 156 Recommendation 3.6.2 (page 24)

Recommendations following the assessment must address basic and immediate needs of the individual being assessed, and assist them in accessing required resources.

The core principles of bioethics, including autonomy and consent, confidentiality, beneficence, and non-maleficence must be carefully applied.

### Communicating the results of assessment

SIGN 156 Recommendation 4.1.1 (page 27)

Education about the impact of FASD and appropriate support for the individual and those involved with their care is recommended. The range of potential issues that might be expected to arise as a result of receiving the FASD diagnosis/descriptor should also be discussed. It is important that this information is communicated in a culturally sensitive manner using appropriate language.

### Follow up

SIGN 156 Recommendation 4.1.2 (pages 27-28)

A member of the team around the child should follow up within a specified length of time to ensure that the recommendations have been addressed and to provide further support as needed.

Individuals with FASD and their caregivers should be linked to resources that can improve outcomes. However, just because availability of services is limited, an individual should not be denied an assessment and management plan. Often the identification of need is the impetus that leads to the developmental of resources.

When young adults are transitioning to independent or interdependent living situations, they may need to undergo a reassessment to identify any changes in their adaptive function scores and to make any subsequent adjustments to their management plan.

* + 1. Current UK practice

No current practice information was identified for management and follow up. The BMA report [Alcohol and pregnancy: Preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy) states that there is no specific commissioning of services for the management of FASD, that there are no frameworks for the clinical management of FASD in the UK, and that services to which people are referred may not have the skills required to manage FASD effectively.

* + 1. Resource impact

If follow up appointments increase as a result of the quality standard, then that could have a significant resource impact. This would depend on current activity and whether follow up was done in primary or secondary care.

* 1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 10 December 2019.

### Training

The training of different groups of professionals and practitioners on a range of topics, including FASD and the risks of alcohol in pregnancy, was suggested as an area of quality improvement. This suggested area has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee should consider which parts of care and support would be improved by increased training. Training may be referred to in the audience descriptors.

### Need for national FASD strategy

This suggestion has not been progressed. Quality standards focus on areas for quality improvement that can be addressed by local commissioners. National strategies are outside the scope of quality standards.

### Recognition of FASD as neurodevelopment disorder / lifelong disability

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support. The committee should consider which parts of care and support would be improved by recognition of FASD as neurodevelopment disorder / lifelong disability.

### Public health policy / regulations

This suggestion has not been progressed. Quality standards focus on areas for quality improvement that can be addressed by local commissioners. Regulations are outside of the scope of a quality standard and public health policy is the remit of Public Health England.

### New / amended guidelines

Suggestions included a formal FASD diagnostic guideline; a guideline on interventions for women at high risk of PAE; and amending other NICE guidance to reference FASD. This area has not been progressed because additional and amended guidance is outside of the remit of quality standards. Suggestions for additional guidance will be passed on to the organisations that refer topics to NICE for development as a guideline.

### Meconium testing of newborns

This suggestion has not been progressed as there are no relevant recommendations in the source guidance.

### Better parenting interventions

This suggestion has not been progressed as there are no relevant recommendations in the source guidance.

### Identification of people at risk of alcohol ‘harm’

This suggestion has not been progressed as it is outside of the scope of this quality standard. The NICE quality standard on [alcohol-use disorders](https://www.nice.org.uk/guidance/qs11) covers identifying and supporting adults and young people who may have an alcohol problem.

### Long Acting Reversible Contraception

This suggestion has not been progressed as it is outside of the scope of this quality standard. Long Acting Reversible Contraception is covered by the NICE quality standard on [contraception](https://www.nice.org.uk/guidance/qs129).

### Coordination and continuity of care

Coordination and continuity of care were suggested using different methods, such having a coordinator, lead professional or a person-centred plan. This is covered by the NICE quality standards on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/qs15) and [transition from children’s to adults’ services](https://www.nice.org.uk/guidance/qs140). Infant, children and young people's experience of health care gas also been referred to NICE for development as a quality standard, but development has not yet started on this topic.

### Annual audit of maternity notes and national recording of FASD data

These suggestions have not been progressed. Audit and data collection are methods by which quality improvement can be evidenced. Quality statements focus on actions that demonstrate high quality care or support, not the methods by which evidence is collated. However, audits and suggested methods of data collection may be referred to in the data sources for quality measures.

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# Appendix 1: Diagnostic algorithm for FASD[[18]](#footnote-18)

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# Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

**General comments (includes contextual information, additional sources**

| **ID** | Stakeholder | Comment |
| --- | --- | --- |
| General comments | | |
| 1 | DHSC | Alcohol exposed pregnancies present a significant public health problem across the country; the UK has the fourth highest level of prenatal alcohol use in the world. Foetal Alcohol Spectrum Disorder (FASD) is an increasingly recognised condition resulting from pre-natal alcohol exposure, an umbrella term that covers a range of diagnoses.  Foetal Alcohol Syndrome (FAS) is the most clinically recognisable form of FASD. The clinical features of other forms of FASD are less well defined and are more complex to diagnose.  FASD can cause physical, mental and behavioural problems in childhood, persist-ing throughout life. Its effects are diverse and range from cognitive and sensory processing issues and Attention Deficit Disorder, to heart problems and concerns with bones and organs. Quite often people with FASD have multiple diagnoses. As referred to in NHS Choices information on Foetal Alcohol Syndrome, the condition is entirely preventable if there is zero alcohol exposure throughout pregnancy. This is further supported by the Chief Medical Officer (CMO) and National Institute for Health and Care Excellence (NICE) guidance. FASD may not be detected at birth but sometimes becomes apparent later in life. It carries lifelong implications for the individual, and international evidence highlights the significant economic cost to so-ciety in terms of lost productivity, with impacts on the health, social care, education, and criminal justice systems.  FASD can have a significant impact on the early year’s development of children and their life chances. Early intervention services can help reduce some of the effects of FASD and support some of the secondary disabilities that result. Responsibility for commissioning FASD services lies with NHS clinical commissioning groups working together across all sectors.  PHE and NHS England and local commissioners are already undertaking awareness  and education on the prevention agenda on the dangers of drinking alcohol while pregnant. For example, the Greater Manchester Health and Social Care Partnership has just launched its Trimester campaign to raise awareness of drinking alcohol when pregnant: <http://www.drymester.org.uk/>  Midwives and health visitors have a central role in providing clear, consistent advice and early identification and support. The Department of Health and Social Care and its Arm’s Length Bodies are reinforcing that role through several central strategies:   * Through the Maternity Transformation Programme to promote safer maternity services. * The National Institute for Clinical Excellence has updated its guidelines “CG62 Antenatal care for uncomplicated pregnancies” to reflect the CMOs’ guidelines not to drink during pregnancy. * Working with the Royal Colleges and regulatory bodies to raise the profile of the CMOs’ guidelines and recommend they include within their training. * To help better inform consumers by including the UK CMOs' advice not to drink during pregnancy on the labelling on alcohol drinks.   The Government acknowledges there is still some way to go on improving services and diagnostics for those with FASD and that is why the Deputy Chief Medical Officer, Professor Gina Radford led two stakeholder events co-hosted with the National Organisation for Foetal Alcohol Syndrome (NOFAS) UK in autumn 2018 to discuss the latest evidence base, learn about current good practices, identify problem areas and consider options for the development of future policy.  The main messages from the events included:   * Not enough is happening on prevention - people still think they can consume alcohol when pregnant; * Education and awareness are poor in the health and care system on FASD; * FASD is not just a health and care problem - it impacts on education, employment, the benefit system and justice; * The diagnosis and treatment pathway are often too lengthy and poor; * There is no central data on FASD prevalence.   The Committee may be interested to know that FASD funding made available section 64 funding as part of the Children of Alcohol Dependent Parents programme (CADEP). Funding of up to £473k for the voluntary sector that will support grassroots initiatives to prevent cases of Foetal Alcohol Spectrum Disorder and help improve support for those living with its consequences. The FASD grant is live for bids to commence in the financial year 2020/21. It is available here: <https://www.gov.uk/government/publications/funding-to-support-work-around-foetal-alcohol-spectrum-disorder>  [DHSC also provided NICE with a 4-page list of resources from the UK, Canada and USA. For the sale of brevity they are not repeated here.] |
| 2 | FASD Network UK | FASD Network UK is a national FASD organisation that has focused its intensive work with more than 1000 families in a single geographical location thereby providing the largest direct family support for FASD in the UK. The key areas for improvement in the discussion below are comments that our families highlight and which we also witness from ongoing direct work. |
| 3 | Neurological Alliance | Tees, Esk and Wear Valley Mental Health Foundation Trust are currently developing a neuro-developmental service but as yet not confirmed FASD will be included. |
| 4 | Public Health England | PHE is developing a Maternity Prevention Pathway, a digital resource which guides practitioners, clinicians and commissioners to the evidence and “what good looks like”; one element of content will be “reducing the incidence of pregnancies harmed by alcohol”. This will be published March 2020. |
| 5 | Public Health England | PHE and the Department of Health and Social Care are on the threshold of refreshing and re-writing the Healthy Child Programme. This can be viewed at: <https://www.gov.uk/government/publications/healthy-child-programme-pregnancy-and-the-first-5-years-of-life>.  The Healthy Child Programme, its accompanying commissioning guidance and clinical guidance (High Impact Areas) will be refreshed over the next 18 months. The first chapters will have the same content as the Maternity prevention pathway. The Healthy Child programme will start with the pre-conception period.  There are six High Impact Areas for pre-school children and six for school age. The link to all the HIAs published so far can be found here: <https://www.gov.uk/government/publications/commissioning-of-public-health-services-for-children>  PHE is developing six High Impact Areas for pre-conception to birth |
| 6 | SCM6 | “The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study,” Christie L.M. Petrenko Ph.D, Mary E.Pandolfino, Rachael Roddenbery, Research in Developmental Disabilities, Volume 59, December 2016, Pages 255-267. See: <https://www.sciencedirect.com/science/article/abs/pii/S0891422216302025> and “How thinking about behavior differently can lead to happier FASD families” <https://www.rochester.edu/newscenter/how-thinking-about-behavior-differently-can-lead-to-happier-fasd-families-189582/>   How Personal Perspectives Shape Health Professionals’ Perceptions of Fetal Alcohol Spectrum Disorder and Risk  Kerryn Bagley and Dorothy Badry, Int. J. Environ. Res. Public Health 2019, 16, 1936; doi:10.3390/ijerph16111936  <https://www.mdpi.com/1660-4601/16/11/1936> “This article examines how health, allied health and social service professionals’ personal perspectives about alcohol and the risks associated with alcohol consumption become non-clinical factors that may influence their professional practice responses in relation to fetal alcohol spectrum disorder (FASD). It presents findings derived from a qualitative, interview-based study of professionals from a range of health, allied health and social service professions in New Zealand.”  Outcomes and needs of health and education professionals following fetal alcohol spectrum disorder-specific training, Reid, White, Hawkins, Crawford, Liu, Shanley, J Paediatr Child Health. 2019 Aug 29. doi: 10.1111/jpc.14608. <https://www.ncbi.nlm.nih.gov/pubmed/31463992>  NOFAS-UK/OnePoll data collected April 2019 from 2000 adults across the UK showed that 1/3 of those in child-bearing years did not recognise the current CMO guidance. (Unpublished, data available upon request) |

| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **Raising awareness** | | | | | |
|  | CoramBAAF | Prevention of FASD by ensuring that all women of childbearing age are aware of the risks of any alcohol consumption in all stages of pregnancy | FASD is preventable  Need to increase public awareness and young people should receive education at school  Health and social care staff need to give consistent messages. | Reduce morbidity | Relevant publications that have informed our response for the quality improvement standards suggested:-  Adoption and Fostering Journal 3/15 vol 39 October 2015 .Special Edition FASD CoramBAAF  Dealing with Foetal Alcohol Spectrum Disorder. Good Practice Guide (Mather 2018) CoramBAAF |
|  | DHSC | Prevention | Support local areas to implement prevention campaigns to pregnant women and those planning to get pregnant to not drink alcohol during pregnancy. |  |  |
|  | FASD Greater Manchester | Raising awareness of the risk of drinking while pregnant | To reduce the number of cases of FASD | So that the individuals have the correct information to make an informed choice about alcohol in pregnancy. Professionals are still giving out incorrect information and mixed messages about alcohol in pregnancy. Until this message is clear people may not accept the diagnosis and difficulties associated with FASD. | We are a support group so raising awareness of the risks is very important, but it is often forgotten, as families try to navigate their way through their own difficult journey  Alcohol guidelines for pregnant women, barriers and enablers for midwives to deliver advice. August 2019  Greater Manchester’s Alcohol Exposed Pregnancy campaign |
|  | FASD Network UK | Recognition of FASD as a prevalent but preventable lifelong disability that qualifies for public health attention, disability services and legislative protections. | There is no formal, national prevention campaign to bring awareness of the harms of prenatal alcohol despite the CMO guidance from 2016 of ‘No Alcohol in Pregnancy’.  If we are not recognising FASD and its causal factors, then we are seeing this condition continue unabated. The 1000 families registered at FASD Network UK affected by FASD in just our region will be an under-estimate of the levels of need and there will be many more who don’t have a diagnosis or come to seek support from our FASD specialist organisation.  Many families with a child with FASD are not deemed as having a disability and are therefore ineligible for disability services or SEND provision or social care support that they would attract if they were given disability status.  We have evidence of excellent prevention practices in some of our local public health teams who have embedded Audit C’s, have posters in clinics, leaflets in booking packs, trained all midwives and health visitors, have training alcohol support agencies, have embedded PHSE lessons and used creative arts such as animations and drama to communicate this message. If some public health teams can do it as part of their alcohol harm reduction strategies then it is possible for everywhere to take responsibility for raising awareness of and potentially preventing FASD. | When we have attended local health scrutiny meetings and commissioners are asked to account for how many people with FASD are in a given area, they can’t find them or may come back with a handful identified from hospital episode statistics. We have a more accurate informal list from our support groups than they do. This is not acceptable. It remains a hidden disability due to the poor quality health surveillance systems that are not fit for purpose.  Without the correct identification and coding (there are multiple confusing diagnostic codes currently being used), local CCG’s are not commissioning services for people with FASD as there is no evidence of need, nor are they providing robust public health campaigns for the prevention of FASD.  A diagnosis that is denied or not acknowledged by practitioners and service providers does not then get the legislative protection for services that other parallel conditions currently have. This blatant discrimination where one neuro-developmental condition gets services and another one cannot must not continue. | BMA Guidance on FASD  BMJ Guidance on FASD  SIGN Guidance Scotland <https://www.sign.ac.uk/assets/sign156.pdf>  <https://pathways.nice.org.uk/pathways/alcohol-use-disorders> |
|  | Neurological Alliance | Prevention | Every individual has a different susceptibility to alcohol so it is not sufficient to allow a ‘few units’. Advice must be in line with changing societal attitudes to binge drinking. Many people drink at home to relax, it is the “norm” to share a bottle of wine and have a couple of G & T’s every night. A high number of pregnancies are un planned.  We need a strong national public health message - similar to the AIDS campaign. This message needs to be on the curriculum for PHSE in schools and youth clubs with sexual health messages.  GP surgeries need to have publicity posters. Health professionals must give clear advice in line with other European countries.  The full scope of NHS disciplines, Social workers and education SEN coordinators need to understand the lifelong psychological impact of living with FASD. Social workers will be dealing with adults who are not diagnosed and will be unable to or need additional services to parent in the future. | It is a public health issue that is preventable. | <http://www.na-tvdny.org.uk/wp-content/uploads/2019/09/FASD_Brochure-web.pdf> |
|  | Northumbria Healthcare Foundation NHS Trust | Additional developmental areas of emergent practice | Maternity health professionals to engage with local multi agency alcohol partnership groups to raise the issue of reducing alcohol in pregnancy, and to set and measure meaningful objectives to provide a seamless service that meets the needs of pregnant women and their families. To utilise existing initiatives which address alcohol in pregnancy to facilitate a greater awareness and facilitate prevention.  Prevention of FASD and raising awareness of PAE should be included in all relevant primary care services and gynaecology clinics.  Standardised, mandatory FASD and PAE training for maternity staff should be delivered annually in protected time and preferably face to face. Consistent information and practices should be shared and regularly updated with latest evidence and guidelines. | To ensure that commissioning prioritises alcohol screening in pregnancy.  Specialist services need to be flexible, immediately accessible and conveniently located to meet the needs of women in urban and rural locations. A clear communication arrangement is required so that women receive a seamless service and maternity staff are kept informed of each woman’s engagement with the service to monitor her progress and provide the relevant additional support. | Specific maternity alcohol support would be the gold standard.  Recommendations taken from research submitted for publication.  ‘Working across boundaries to provide and commission maternity services to support personalisation, safety and choice, with access to specialist care whenever needed.’ Better births.  Addresses health inequalities. Guidance for NHS commissioners on equality and health inequalities legal duties https://www.england.nhs.uk/wp.../hlth-inqual-guid-comms-dec15.pdf |
|  | Royal College of Paediatrics and Child Health | Availability for referral to and access of specialist services for those intending to conceive alongside education of the risks of FASD. | Evidence suggested increasing levels of alcohol consumption (estimated at 75%) in the fertile age groups, as well as increased single episodes of heavy drinking (14% report drinking 6 or more units in a day). | Aiming to reduce the incidence of FASD through education explanation of high-risk behaviours, especially, but not limited to, those who are at increased risk of these behaviours. | BMA Alcohol in Pregnancy and Managing FASD report, updated 2016 |
|  | SCM1 | Education around and prevention of FASD | The greatest impact on this totally preventable brain damage will come from prevention long term. Prevention can only happen if a nation is educated about the dangers of alcohol consumption in pregnancy and exactly what it does to the development of a foetus. | We have the opportunity to guide an entire nation on this because currently the education that happens is usually from people with lived experience who are impacted by FASD. There are still masses of medical professionals who know nothing at all about FASD and are honest enough to admit that. No matter what work we do to make life accessible for people with FASD, nothing will have a greater impact than working towards preventing it happening in the first place. |  |
|  | SCM5 | To improve education for people who are pregnant regarding the harms of alcohol in pregnancy | As a preventable disorder educating when relevant to people to hear message consistent with DOH guidance. Alcohol consumption is higher than anticipated in the UK  BMJ board of science document  Quantitative and Qualitative research in this area  SIGN guidance | There is inconsistent messaging and education meaning many ignore message. Whilst important not to scare people it is important to give accurate information. The UK has some of the highest rates of alcohol exposure in the world for women drinking during pregnancy and the knowledge of professionals is poor | * Popova S, Lange S, Probst C, Gmel G, Rehm J. Estimation of national, regional and global prevalence of alcohol use during pregnancy and FAS: a systematic review and metaanalysis. Lancet Global Health. 2017;5:e290- e9. * SIGN. SIGN 156. Edinburgh: Health improvement Scotland; 2018. * BMA Board of Science. Fetal Alcohol Spectrum Disorders, a guide for healthcare practitioners update. London; 2016 2016. * Mukherjee RAS, Wray E, Curfs L, Hollins S. Knowledge and opinions of professional groups concerning FASD in the UK. Journal of Adoption anf Fostering. 2015;39:212-24. * Mukherjee RAS, Wray E, Hollins S, Curfs L. What does the general public in the UK know aout the risk to the developing foetus if exposed to alcohol in pregnancy? Findings from a /uk mixed methods study. Child Care,Health and Development. 2014;41(3):467-74. * McQuire C, Mukherjee R, Hurt L, Higgins A, Greene G, Farewell D, et al. Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study. Preventive Medicine. 2019;118:344-51. * Scholin L, Watson J, Dyson J, Smith L. Alcohol Guidelines for pregnant women. London: Institute of alcohol studies; 2019. |
|  | SCM8 | Preconception education | Preconception education regarding the risks of drinking alcohol in pregnancy. Preconception health relates to the health behaviours, risk factors and wider determinants for women and men of reproductive age which impact on maternal, infant and child outcomes.It is also about ensuring that services can take a forward view to promote healthy behaviours and support early interventions to manage emerging risks across the lifecourse, prior to first pregnancy, and then looking ahead to the next baby and beyond.  Women are not aware of the risks of consuming alcohol in pregnancy and information provided is inconsistent via healthcare professionals. | Consistent information should be provided and set from clinical bodies.  Avoiding alcohol and substance misuse Alcohol is a ‘teratogen’, which means that it can affect fetal development and cause birth defects or complications during pregnancy. Fetal alcohol spectrum disorder (FASD) is an umbrella term for conditions that can occur in a person whose mother consumed alcohol during pregnancy. The most severe form is known as fetal alcohol syndrome. Even at consumption levels of 1-2 units/day, there are increased risks of poor pregnancy outcomes, which rise with rising  consumption. Effects of different drugs of misuse during pregnancy are broadly similar and are largely non-drug specific. Intra-uterine growth retardation and pre-term deliveries contribute to increased rates of low birth-weight and increased perinatal mortality rate. These outcomes are multifactorial and are also affected by factors associated with socio-economic deprivation, including smoking. | Making the case for preconception care  <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/729018/Making_the_case_for_preconception_care.pdf> |
|  | TACT | Greater awareness of the dangers of drinking whilst pregnant | To reduce the numbers of children who are foetally affected.  We will never totally eradicate Foetal Alcohol Spectrum Disorders in our society as we have a culture that means women are drinking before they are aware that they are pregnant | Conflicting ambiguous advice for years has led to a lack of knowledge in the general public.  There needs to be a clear message (through a public health strategy) that if you are pregnant, or trying to get pregnant, then no level of alcohol is safe |  |
|  | UK National FASD Clinic, Surrey and Borders NHS Trust | Prevention of FASD – specifically increasing everyone’s awareness of the importance of abstaining from alcohol whilst pregnant including clear and consistent messaging about the risks of drinking during pregnancy | FASD is caused by drinking alcohol during pregnancy and as such it is potentially preventable.  Chief Medical Officer guidance (2016) is to abstain from alcohol completely during pregnancy. | A recent report by the Institute of Alcohol Studies cited research showing that only 58% of midwives are aware of the existence of Chief Medical Officer guidelines regarding alcohol use during pregnancy.  It is good that the CMO guidelines state the safest approach is to not drink alcohol at all during pregnancy; however there is other information in the guidelines and on the NHS website is potentially misleading.  In both the CMO guidance and on the NHS website, the phrase “drinking heavily during pregnancy can cause a baby to develop fetal alcohol syndrome” is used. Firstly it is not specified what is meant by ‘drinking heavily’ and this may be misinterpreted. The CMO guidance itself states ‘women…need to be careful to avoid under-estimating their actual consumption’; and using terms such as ‘drinking heavily’ may fuel this underestimation. For example, Mukherjee et al (2013) showed that when pouring drinks, individuals are not accurate in estimating the alcoholic content of each drink. When asked to pour what they would normally pour, some individuals poured up to 456% more than a single unit of alcohol.  Secondly there is a risk that the CMO guidelines and information on the NHS website will be interpreted to mean that only ‘heavy’ amounts of alcohol will result in the most ‘severe’ difficulties. For example, the Chief Medical Officer guidelines point 29 says: “Drinking heavily during pregnancy can cause a baby to develop fetal alcohol syndrome (FAS)”. Then in point 30 it goes on to say: “Whilst FASD is less severe than FAS…” This is misleading and may be inaccurate. The term ‘FAS’ in this context means that there are growth restrictions and sentinel facial features as well as Central Nervous System (CNS) deficits. [Using the SIGN guidance cited in the topic overview and the Canadian 2016 guidance the term ‘FAS’ would be equivalent to ‘FASD with sentinel facial features’]. Whether it is termed ‘FAS’ or ‘FASD with sentinel facial features’, this condition is not necessarily more severe than FASD without sentinel facial features in terms of brain dysfunction and ‘heavy’ amounts of alcohol are not required for a diagnosis. There is no agreed threshold of alcohol use that results in FAS with or without facial features – the facial features are more about timing than dose. It can be said that more alcohol is more risk, and no alcohol is no risk, but we should be careful not to imply (even by accident) that only heavy drinking results in severe CNS outcomes. There is evidence that even a single episode of binge drinking may have measureable neurodevelopmental effects in humans and animals (please see Canadian Guidance 2016, Appendix pg. 16), and a threshold of 2 binge episodes is recommended as minimum for diagnosis.  Additionally, on the NHS website it states “drinking alcohol, especially in the first three months of pregnancy, increases risk of miscarriage, premature birth and your baby having a low birth weight”. In the next paragraph it says “drinking after the first three months of your pregnancy could affect your baby after they are born”. This seems misleading as it implies that problems with the baby after it is born (i.e. including FASD) only occur if drinking occurred later than the first 3 months of pregnancy - please see Appendix of the Canadian Guidance again for evidence that exposure to alcohol during the first three months of pregnancy can affect physical and neurodevelopmental development (pg. 16) | Cook JL, Green CR, Lilley CM, Anderson SM, Baldwin ME, Chudley AE et al (2016) Fetal Alcohol Spectrum Disorder: a guideline for diagnosis across the lifespan. CMAJ 2016; 188 (3) 191-7. Appendix  Department of Health, 2016. UK Chief Medical Officers’ Low Risk Alcohol Guidelines. London.  Mukherjee, R, Wray, E, Curfs, L & Hollins, S (2013) *Estimation of alcohol content of wine, beer, and spirits to evaluate exposure risk in pregnancy: Pilot study using a questionnaire and pouring task in England.* International Journal of Alcohol and Drug Research  NHS Website ([www.nhs.uk](http://www.nhs.uk)) – search ‘your pregnancy and baby guide’ ‘drinking alcohol while pregnant’  Scholin, L, Watson, J, Dyson, J. & Smith, L (2019) *Alcohol Guidelines for Pregnant Women: Barriers and Enablers for Midwives to Deliver Advice.* Institute of Alcohol Studies Report. |

| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| Identification of children and young people at risk of FASD | | | | | |
|  | British Pregnancy Advisory Service | Thorough examination of calls for ‘Thorough’ alcohol screening for all pregnant women (including the consideration of further research in to the use of biomarkers). | We take issue to the notion of mandatory universal screening for maternal alcohol consumption, as included in SIGN 156, ‘Reducing Alcohol-Exposed Pregnancies in Greater Manchester’ Strategy Papers, and suggested at the Informal Roundtable on Forthcoming NICE Quality Standard on FASD (17 May 2019). We are of the opinion that no adequate ethical assessments have been carried out with regards to universal screening of this kind, and that no further information has been suggested with regards to how the results of such a screen will be subsequently used and stored. We are concerned that mandatory screening will erode models of informed consent, and the privacy interests of women could be overshadowed by unproven risk.  Furthermore, we are of the opinion that the decision to further research into the use of biomarkers is one not to be taken lightly.  Within literature surrounding PAE, there is a longstanding conflation between evidence of PAE and diagnosis of FASD. Within this context, the decision to further such research embeds such a conflation into UK policy. | We are of the opinion that policy is being developed within the UK concerning alcohol screening for all pregnant women, without the necessary ethical assessments or evaluations as to whether such a policy is proportional. We would argue that before such a notion is considered for inclusion within NICE Quality Standards, such processes would need to be adequately considered and completed.  Furthermore, the very consideration of objective biomarkers implies an ethical consensus that this is a reasonable suggestion for establishing PAE. This implied, false consensus is inherently linked to the claims that women underreport their alcohol consumption during pregnancy. Therefore the use of biomarkers would solve this issue. We are of the opinion that nothing a woman could do during pregnancy warrants the use of such an invasive screen in order to circumvent her right to privacy. | There is a complete lack of ethical evaluation of both the implementation of alcohol screening for all pregnant women, and the use of biomarkers within a UK context.  Furthermore, the assessment of whether further research should be conducted in relation to the use of biomarkers would need to be made against the backdrop of the Canadian context. The use of biomarkers (meconium) is part of the Canadian Toolkit for FASD, and the SIGN guidelines were drafted with heavy reference to Canadian policy. We are of the opinion that such evidence would necessitate a higher level of scrutiny following the collapse and discredit of ‘Motherisk’, the Canadian lab involved in the use of biomarker screening, who further produced key supporting documents for Canadian policy. |
|  | British Pregnancy Advisory Service | The creation of new obligations during pregnancy which are enforced through changes in policy (i.e. mandatory screening) | Public authorities have a legal responsibility to assess their activities/set out how they will protect individuals from discrimination on the basis of ‘protected characteristics’: including pregnancy and maternity.  There is an argument that pregnant women are being unduly targeted for more invasive intervention (in compared to screening/intervention for alcohol within the general population- which is routinely rejected by the UK Screening Committee). Such processes run the risk of alienating women from healthcare situations, and subjecting them to undue vulnerability in terms of being implicated for a wide range of neurodevelopmental effects, which are not proven to be caused by quantified alcohol consumption.  The suggestions for how guidance should be developed- as supported by advocacy groups such as NOFAS- mean that pregnant women are subjected to ‘mandatory’ screening processes/different treatment by the very virtue of being pregnant. | See for example, <https://legacyscreening.phe.org.uk/screening-recommendations.php> : Alcohol misuse:  “The UK NSC looked at research on whether any tests were good enough to use for a whole population screening programme and whether screening improves health in the long term. Population screening for alcohol misuse is not recommended because: • the most common tests for alcohol misuse are questionnaires which are unsuitable when used within a whole population screening programme. This is because, when used in millions of people thousands would be wrongly told they needed follow on advice when they did not, potentially overwhelming services and reducing access for those who could benefit • different people can safely drink different amounts of alcohol, depending on factors such as their age, sex and ethnicity. For a screening test to be reliable it will have to consider these factors by defining test ‘cut-off levels’. We didn’t find any agreement on what these levels should be in the diverse UK population • the review did not find any research that showed a whole population screening programme would help to reduce the harms from alcohol misuse in the long term.”  This however, does not seem applicable to pregnant women, where it is repeatedly suggested that all pregnant women should be screened to identify pregnancies ‘at risk’ of FASD |  |
|  | CoramBAAF | Identification of infants, children and young people at risk of FASD.  Health , social care and education professionals can recognise/ identify children who require assessment for FASD. | Information regarding alcohol use during pregnancy is required during diagnostic process.  This information is sometimes not available particularly for children who no longer live with their birth parents. Midwives and other health and social care professionals should record this information clearly and the information should be available in the childs health and social care record. | Improve timely access to assessment.  Need to increase professional awareness of presentation of FASD. |  |
|  | FASD Awareness South East | CCG-led recurring campaign with Public Health to increase awareness of the Chief Medical Officer's advice on alcohol consumption during pregnancy in GP surgeries, secondary schools and colleges. | To raise awareness of FASD, to help with prevention, education and understanding to reduce the prevalence of the condition, especially in the younger generation. | So the general population can open up their minds and their dialogues to be informed and educated around this condition and reduce stigma. Drinking while trying for a baby and while pregnant needs to be viewed as a public health issue in the same way as drinking and driving, smoking, etc. Everyone needs to understand and support healthier lifestyle changes for the benefit of the generations to come. | The evidence of a catalogued history of alcohol consumption is one of the key factors in obtaining a referral and potential diagnosis |
|  | Greater Manchester Health and Social Care Partnership | Universal alcohol screening in pregnancy with enhanced support for women who continue to use alcohol following midwife’s advice and information. Alcohol history must be included on paediatric records. | Routine alcohol screening and alcohol brief interventions throughout pregnancy reduce the likelihood of an alcohol exposed pregnancy | Barry, K. L., Caetano, R., Chang, G., DeJoseph, M. C., Miller, L. A., O’Connor, M. J., Olson, H. C., Floyd, R. L., Weber, M. K., DeStefano, F., Dolina, S., Leeks, K. (2009). *Reducing alcohol-exposed pregnancies: A report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects*. USA: Centers for Disease Control and Prevention.  O’Connor, M. J., & Whaley, S. E. (2007). Brief intervention for alcohol use by pregnant women. *American Journal of Public Health,* 97(2), 252-258. |  |
|  | National Organisation for Foetal Alcohol Syndrome-UK | Information about the CMO guidance on alcohol in pregnancy and FASD should be posted in GP and Paediatrician surgeries and relevant clinics. | * The CMO guidance can potentially avoid FASD and should be visible. * Increased visibility regarding FASD can raise awareness, help access to diagnosis and care and facilitate those families accessing supportive peer-to-peer networks. | Knowledge about CMO guidance is patchy. “Buy-in” from some professionals is even more challenging – with conflicting information being given out and causing confusion.  The CMO guidance has never had a full PR campaign of its own (it was wrapped up in other guidelines). | * Many birth mothers of children with FASD report in helpline calls to NOFAS-UK anecdotally that they were not aware of the risks of alcohol in pregnancy and that they receive conflicting advice from their GPs and other healthcare professionals about the risks – with confusion about low levels still lingering. This matches with a recent poll conducted by NOFAS-UK of 2000 adults across the UK that showed that approximately 1/3 of those of childbearing age are unable to recognise the current CMO guidance. (Data unpublished but can be provided to the committee upon request.) * The BMA makes clear that: “It is crucial that women who are pregnant or considering a pregnancy are provided with clear, reliable guidance on alcohol consumption that minimises the risk of harm. See action suggested as a result of the BMA “Alcohol in Pregnancy” report: “https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy * As an example of the mixed messages given out by professionals, last year NOFAS-UK ended up in a twitter conflict with a pregnant GP who was tweeting publicly about the fact it was safe for her drink low levels of alcohol during her pregnancy and attacking NOFAS-UK for sharing the CMO guidance. This had devastating impact on those with FASD and their families/caregivers. |
|  | National Organisation for Foetal Alcohol Syndrome-UK | Screening pregnant women for alcohol use | Repeated and open-ended discussions (motivational interviews) with women about alcohol use in pregnancy can help prevent FASD | * Provision of this information is patchy at the moment and the training in using these techniques is not standardised – including training for GPs so that women receive information when first pregnant before referral to a midwife. | * The Institute for Alcohol Studies recent report details the need for increased midwives training <http://www.ias.org.uk/News/2019/16-September-2019-Midwives-call-for-more-support-to-deliver-alcohol-advice.aspx> * The Greater Manchester Alcohol Exposed Pregnancies programme is yielding positive results and is a source of information on best practices. * The NOFAS-UK helpline regularly receives feedback from women who are confused by the mixed messages they have received. * The UK-EU Birth Mothers Network-FASD reported on the need for more supportive screening and help for those who find it difficult to stop drinking. See for example, Pip Williams, “There needs to be a compassionate non- judgmental empathic pathway that creates trust, where social care and health care professionals work together with the women to help them have healthier pregnancies and give their child the best start in life.” Presentation n Attachment G, “OUR FORGOTTEN CHILDREN, The Urgency of Aligning Policy with Guidance on the Effects of Antenatal Exposure to Alcohol,” A Roundtable Discussion with FASD Stakeholders Co-chaired by Professor Sheila the Baroness Hollins and Mr Bill Esterson, MP Houses of Parliament • 23 May 2018. <http://www.nofas-uk.org/WP/wp-content/uploads/2018/06/20180523_Report_FIN.pdf> |
|  | Northumbria Healthcare Foundation NHS Trust | Any maternal disclosure of alcohol consumption in pregnancy must be documented in the antenatal notes. | To facilitate diagnosis. Documented evidence is generally a requirement of diagnosis for children without the classic FAS facial dysmorphia. | To utilise resources already available to us such as the (red) baby book as this follows the infant throughout childhood. It may be an effective resource to share information with the health visitor, GP, school nurse, teacher or even social worker if required. A special Prenatal Alcohol Exposure (PAE) question in the book could be added and completed in the antenatal period as a simple way to communicate. Any PAE could also be documented in a Regional Perinatal Data Management system such as BadgerNet UK, and all baby notes and electronic records should routinely be shared with the multidisciplinary team. |  |
|  | Northumbria Healthcare Foundation NHS Trust | To develop and standardise alcohol screening practices, services and patient pathways across the country. | To facilitate early detection of at risk mothers and babies to target referrals and support regardless of location | To educate women and their families and prevent future harm to unborn children and reduce prevalence rate of children with FASD Disability.  The public is still largely unaware of the new CMO guidelines from 2016 regarding alcohol in pregnancy.  ‘Alcohol guidelines for pregnant women: Barriers and enablers for midwives to deliver advice’.2019 | It is estimated that 41.3% of women in the UK consume alcohol during pregnancy; the fourth highest in the world. Popova, S., et al., 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): p. e290-e299.  Prevalence rates of FASD in children in the UK are unknown, but FASD symptoms have been identified in 6-17% of a large scale, longitudinal cohort study. McQuire, C., 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: p. 344-351.  Aligns to Better Births. ‘Where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred around their individual needs and circumstances.’ |
|  | Northumbria Healthcare Foundation NHS Trust | An antenatal specific screening tool should be considered to maximise the detection of women consuming alcohol in pregnancy, which incorporates all significant information. A universally agreed referral threshold is required. | To ensure that every woman receives equitable support across the country.  A combined role of smoking cessation/alcohol/public health advisor in maternity clinics may be a cost effective option to support midwives. | Currently service provision varies dramatically from one NHS Trust to another.  A stepped approach using Brief Interventions have proved effective and is recommended. |  |
|  | Public Health England | Once drinking status has been established it is important for maternity professionals to understand and consistently use current guidance on drinking in pregnancy (both the CMOs’ low risk guidance and CG110). | A recent survey of midwives suggested that a substantial minority (42%) were unaware of the most recent CMOs’ guidance and that many had an inaccurate understanding of the current guidelines. | Please see Alcohol Guidelines for Pregnant Women: Barriers and Enablers for Midwives to Deliver Advice. This can be viewed at: <http://www.ias.org.uk/uploads/pdf/IAS%20reports/rp37092019.pdf> |  |
|  | Public Health England | Being confident that there is rapid support for women who do not stop drinking in pregnancy and accessing that support will have the potential to minimise harm to both mother and child. Develop support for partners of women who drink during pregnancy, to promote a mutually supportive home environment. | The most recent M-BRACE report found that 13% were in cases where a mother had drug or alcohol problems and concluded “*There is very clear evidence of that the care of vulnerable women, particularly those who misuse drugs and alcohol… can be improved*.” | Please see Saving Lives, Improving Mothers’ Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013–15. This can be viewed at: <https://www.npeu.ox.ac.uk/mbrrace-uk/presentations/saving-lives-improving-mothers-care> |  |
|  | Public Health England | Being able to identify whether there is or has been drinking in pregnancy is critical for being able to provide appropriate advice and support to women about the impact on children of alcohol exposed pregnancies | Currently available data suggests only half (52%) of pregnant women have their drinking status recorded at booking. This compares with 83% where smoking status is recorded. | Please see Public Health England (PHE) analysis of the Maternity Services Dataset in Health of women before and during pregnancy: health behaviours, risk factors and inequalities. This can be viewed at:  <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/727735/Health_of_women_before_and_during_pregnancy_national_analysis_of_the_MSDS_booking_data.pdf> |  |
|  | Royal College of Paediatrics and Child Health | An assessment of baseline or background alcohol use should be made at the midwifery booking appointment. | This would help to identify at risk groups and make targeted intervention within the first trimester. | Aiming to minimise the risk to the foetus through minimising exposure. With accurate documentation of the baseline level of alcohol, audit of any intervention would be possible. | NICE Quality Standard – Alcohol-use Disorders: diagnosis and management. QS2: Opportunistic screening and brief interventions  NICE Quality Standard 22 – Antenatal care. QS1: access to antenatal care |
|  | SCM2 | Improvement in quality of maternal alcohol history obtained during neurodevelopmental assessments | Confirmation of diagnosis of FASD without sentinel features can only be made when there is confirmed history of maternal alcohol exposure | Many children with neurocognitive impairment in keeping with FASD but without sentinel facial features are unable to have this diagnosis confirmed without the documented information in the records. | Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html)  British Medical Association (2016) [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy) |
|  | SCM2 | Improved information sharing on maternal alcohol history between primary care and secondary care | Children exposed to maternal alcohol consumption in pregnancy is the main factor causing FASD in the child. Information on maternal alcohol history is needed to make a diagnosis of FASD | At risk children will have relevant surveillance and diagnosis made. Children with FASD will then access the relevant interventions. |  |
|  | SCM3 | Transfer of AEP information onto personalised child health record (PCHR) | To facilitate diagnosis.  As recognised in SIGN guidance 156 - There is no known safe level of alcohol consumption during pregnancy. Even low to moderate levels of prenatal alcohol exposure can negatively impact a fetus and these adverse consequences can persist into adulthood. A lack of access to accurate antenatal health records can be a significant barrier to diagnosis.  PCHR will eventually be digital to further enhance relevant information sharing between services. | Currently discrepancies between trusts in screening and recording alcohol exposed pregnancy. Dependent on maternity systems used and geographical area, even thorough screening may sit within the maternal record. This cannot be easily accessed to aid diagnosis later in life such as in the case of looked after children, or individuals seeking diagnosis where maternal disclosure is not made. | <https://digital.nhs.uk/services/digital-child-health> |
|  | SCM3 | Identification of alcohol exposed pregnancy (AEP) | Standardised approach to screening of women planning pregnancy, already pregnant or at risk of alcohol exposed pregnancy.  Studies such as Scholin et al (2019) highlight that practice variations exist including midwives understanding of the potential impact of prenatal alcohol exposure and their ability and confidence in delivering alcohol brief intervention.  SIGN 156 guidance – ‘A lack of knowledge and understanding of FASD among healthcare professionals means they often  may not feel competent to carry out an assessment and make an appropriate diagnosis. Variation in  knowledge and awareness poses a significant challenge to the implementation of a comprehensive and consistent approach to the management of FASD.’  NB healthcare professionals may vary from maternity settings such as sexual health, primary care and health visiting particularly for preconceptual advice and unplanned pregnancy. | Recognised universal tools such as T-ACE, TWEAK and AUDIT-C could be helpful in screening for risky drinking, however, the authors recommended caution noting that further evaluations of questionnaires for prenatal alcohol consumption should be undertaken.  Specific alcohol screening tool for use within maternity services would be beneficial as universal tools have limitations used within pregnant population – such as perceived acceptability of ‘low-level’ alcohol consumption.  Consideration also needs to be given to the point at which screening and brief intervention is carried out to encompass both early lifestyle advice and accurate recording of alcohol exposure at later gestation. | Please see Scottish SIGN guidance 156 which highlights current evidence and practice  <https://www.sign.ac.uk/assets/sign156.pdf> |
|  | SCM4 | All mothers continuing to drink alcohol in pregnancy should be offered alcohol brief interventions and support to help them reduce and hopefully stop their drinking. Those not responding to brief interventions, or with complex needs including additional substance misuse should be referred to specialist services | Brief interventions have been shown to be effective in terms of economic and health care outcomes with respect to alcohol use. |  | See (for example) :  BMJ 2013;346:e8501 doi: 10.1136/bmj.e8501  <https://doi.org/10.1016/j.amepre.2006.08.028>  There equivalent NICE guidance on smoking (PH48) for example  There is a big gap between mothers who require simple health advice and support from their local midwife or health care provider and those with complex needs referred to specialised services, which at the present is unfilled. – to whom do midwives refer patients for ongoing help and support for brief interventions – very patchy provision. |
|  | SCM4 | At pregnancy booking, all mothers should be screened regarding their alcohol consumption, this information recorded.  Overall Figures regarding the number of women drinking alcohol in pregnancy should be recorded by health providers and collated annually by health commissioners/departments of public health | In the UK, estimates of alcohol consumption in pregnancy are amongst the highest in the world and continues to remain so despite a change in the UK medical officer’s guidance 2016.  Reducing the number of women drinking alcohol in pregnancy is fundamental to reducing the number of children and adults who will be affected by FASD |  | (see Popova et al 2017 doi: 10.1016/S2214-109X(17)30021-9. Epub 2017 )  Information about the proportion of women who drink during pregnancy is difficult to obtain – currently only from a few published research studies.  Without monitoring outcomes, we will be unable to monitor and document improvements resulting from changes to health care policy and education.  Similar improvements have been made in smoking reduction and smoking rates have been monitored |
|  | SCM5 | Consistent history taking and recording of alcohol taken during pregnancy included in Childs notes | There is evidence that there is inconsistent recording of alcohol in pregnancy and inconsistent transfer of this information to child record unlike smoking information | Without the information being transferred because Alcohol exposure knowledge is crucial to diagnosis it is often the single key issue that prevents diagnosis | Scholin L, Watson J, Dyson J, Smith L. Alcohol Guidelines for pregnant women. London: Institute of alcohol studies; 2019.  BMA Board of Science. Fetal Alcohol Spectrum Disorders, a guide for healthcare practitioners update. London; 2016 2016 |
|  | SCM6 | All pregnant women should be screened for alcohol use and any use should be noted in both the pregnant woman’s and the child’s file | Identification of alcohol-exposed pregnancies can provide fundamental information for possible FASD diagnosis should that be required. | Open-ended/non-judgemental (motivational) interview techniques should be used to increase the likelihood of receiving accurate information about alcohol exposed pregnancies  Stakeholders who are foster carers and adoptive parents report great challenges in proving alcohol exposed pregnancies, having any level of alcohol exposure properly noted in the child’s files would provide vital information should the child be assessed at a later point for FASD. | For birth mothers’ perspectives on the importance of discussing alcohol in pregnancy in an non-judgemental way, see, “Meeting with Deputy Chief Medical Officer Prof. Gina Radford Pip Williams, Founder UK-EU Birth Mothers-FASD Network,” 22 October 2018 in  <http://www.nofas-uk.org/WP/wp-content/uploads/2018/11/20181022_Report_FIN.pdf>   For motivational interviewing, see for example: <https://skprevention.ca/alcohol/motivational-interviewing/>  The Greater Manchester AEP programme has extensive information on issues related to how to engage with women on alcohol in pregnancy. |
|  | SCM7 | In Pregnancy: 4. Universal screening of all pregnant women throughout the pregnancy journey (beginning, mid and end - 3 times) and additional support for women who continue to use alcohol following midwives advice in relation to alcohol. |  |  |  |
|  | SCM8 | Antenatal care | Antenatal care to offer consistent advice regarding the risks of drinking alcohol in pregnancy. Alcohol should be discussed at every antenatal appointment with midwife, Obstetrician and the woman. The information provided should be consistent.  Audit C, TWEAk, T-ACE tools for alcohol screening could be suggested to use.  Perinatal institute maternal hand held notes highlight concerns regarding FASD and alcohol use in pregnancy.  Information should be readily available for women to read regarding the risks and drinking alcohol in pregnancy. this differs from Trust.  Alcohol consumption in pregnancy is under reported, the questions are not asked correctly for example: what a unit looks like to the woman, drinking patterns  etc. | As above  All women should be advised not to consume alcohol in pregnancy; additionally those women drinking above the low-risk guideline for the general population should be offered early, brief interventions (ie counselling and/or other services).  Consuming alcohol in pregnancy should be spoken at every point of contact as is the risk of smoking in pregnancy.  Alcohol detoxification should be readily accessible with robust continuing support following detoxification from drug and alcohol services and specialist midwifery support to help the incidence of relapse.  This differs in between Trusts. Some Trusts do not have specialist midwifery support for the women.  Data is very poor for the collection of this data regarding the consuming of any unit of alcohol in pregnancy.  NICE antenatal Guidelines are poor with information to support health care professionals regarding the risk of drinking alcohol in pregnancy. | Data Analysis  <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/727735/Health_of_women_before_and_during_pregnancy_national_analysis_of_the_MSDS_booking_data.pdf>  SIGN, Young people and Children exposed to alcohol.  <https://www.sign.ac.uk/assets/sign156.pdf> |
|  | SCM8 | Postnatal care care of the neonate | Documentation following delivery varies regarding the number of alcohol consumed in pregnancy.  Documentation within the neonatal records again is poor.  Standardised documentation from birth to transfer of care to the health visitor should be initiated at birth. | All postpartum women should be screened for alcohol use with validated measurement tools by service providers who have received appropriate training in their use.  Alcohol consumption in pregnancy should be asked at the 6 week neonatal and postnatal check by the GP and standardised. | SIGN, Young people and Children exposed to alcohol.  <https://www.sign.ac.uk/assets/sign156.pdf> |
|  | UK National Screening Committee | The primary source of guidance for this quality standard is the Scottish Intercollegiate Guidelines Network (SIGN) guideline 156 (2019) ‘Children and young people exposed prenatally to alcohol’.  This guideline includes a recommendation stating that:  ‘*All pregnant and postpartum women should be screened for alcohol use with validated measurement tools by service providers who have received appropriate training in their use. All women should be advised not to consume alcohol in pregnancy; additionally those women drinking above the low-risk guideline for the general population should be offered early, brief interventions (ie counselling and/or other services).* (Chapter 2 Identification of children at risk of FASD Pg 11).  In the UK the UK National Screening Committee (UK NSC) is responsible for advising ministers and the NHS in the 4 UK countries about all aspects of screening and supports implementation of screening programmes; therefore, any recommendation related to population screening during pregnancy falls under the remit on the Committee.  Currently, the UK NSC does not provide any recommendation on screening for fetal alcohol spectrum disorder (FASD). So, screening for FASD should not be prioritised as a key area for quality improvement.  Moreover, the Committee would like to suggest that, if a statement on testing is needed the following text would avoid reference to population screening:  ‘*All women should be advised not to consume alcohol in pregnancy; if the clinician has reason to think the women is drinking above the low-risk guideline for the general population then she should be offered early, brief interventions (ie counselling and/or other services)*’. |  |  |  |

| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **Diagnosis and assessment** | | | | | |
|  | Adoption UK | Clear and timely diagnostic pathway | A diagnosis is the route to understanding the condition and securing support for the individual with FASD as well as their parent(s) or carer(s). | Too often parents and carers have to battle for a diagnosis. Where they are successful, diagnoses often come too late or individuals are mis-diagnosed. Failure to secure an early and accurate diagnosis contributes to the development of ‘secondary disabilities’.  SIGN guidelines state: “Early diagnosis and intervention from birth and in the first years of life can make significant differences to the developmental progress of the affected child, and better understating of the condition can help parents and professionals cope more appropriately with the child’s difficulties. . . If difficulties are not anticipated and understood, educational opportunities will not be optimised and some affected children and young people will have poor educational attainment, develop mental health problems, have a higher risk of becoming addicted to alcohol and other drugs thus continuing the cycle.”  <https://www.sign.ac.uk/assets/sign156.pdf> (page 2). | In 2017, the National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) conducted a GP ‘check-up’ to mark the annual international Foetal Alcohol Spectrum Disorders (FASD) Awareness Day. 41% said they had not received clear guidance from their local Clinical Commissioning Group (CCG) regarding a pathway for diagnosis and support of FASD. And less than a quarter felt ‘strongly confident’ that all those with a FASD were being diagnosed properly.  The *Adoption Barometer* (2019) found that 17% of adoptive parents (UK-wide) suspected that their child may have FASD but do not currently have a diagnosis. Respondents’ comments revealed concerns that FASD is under-diagnosed – with one respondent describing the procedure for getting a diagnosis as a “postcode lottery”.  <https://www.adoptionuk.org/Handlers/Download.ashx?IDMF=fd3d3969-8138-4ede-befd-1018fe629c29> (page 33).  A diagnostic pathway developed by Scottish Government and trialled in Ayrshire is outlined in Adoption UK’s *Foetal Alcohol Spectrum Disorder: Diagnostic challenges and recommendations for the future* (2018) <https://www.adoptionuk.org/Handlers/Download.ashx?IDMF=91c9c083-a3a3-41a1-887b-b3c089c6f7ff> (page 9).  Former junior health minister, Steve Brine acknowledged the barriers to diagnosis in England during a parliamentary debate  <https://hansard.parliament.uk/Commons/2019-01-17/debates/19011751000002/FoetalAlcoholSpectrumDisorder?highlight=fasd#contribution-ED63AF96-FDE0-4C0E-A219-BE7DB02D67F5> |
|  | Adoption UK | Mandatory assessment for all looked after children upon entering the care system, with greater coordination between care system and health authorities. | There is a heightened prevalence of FASD among the care experienced population | High prevalence means there should be a presumption that the child has been exposed to alcohol in the womb and could have FASD.  As mentioned above, earlier identification and intervention have clear benefits for the person with FASD and those caring for the child.  Adopters or foster carers who are taking care of the child have a right to know the needs of a child they are adopting / caring for at the point of placement. | Some estimates suggesting around three-quarters of looked-after children could be affected by the condition e.g. 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, Vol. 39, No. 3 (2015): pp. 225-234.  A joint Adoption UK / BBC survey from 2017 found that more than a third of adoptive parents suspect their child may have FASD.  <https://issuu.com/adoptionuk/docs/bbc_adoption_uk_survey_doc> |
|  | British Medical Association | Diagnostic and referral services for FASD should be commissioned and adequately resourced throughout the UK | Formal diagnosis at the earliest stage is paramount as it permits the implementation of early intervention and treatment programmes. It can also decrease the risk of additional problems commonly found in individuals affected by these disorders that result from neurocognitive deficits.  It is important that diagnosed individuals and their families are linked to appropriate resources and services. | In the UK there are no specific commissioning of services for the diagnostic or management of FASD.  The lack of proper commissioning acts as a barrier to the development of services required to adequately address the needs of individuals affected by prenatal alcohol exposure. | Please see the BMA’s 2007 report, updated in February 2016 on [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy). |
|  | British Pregnancy Advisory Service | Current prevalence estimates and their usage | Prevalence statistics are used in a variety of ways within the source guidance and supporting documents to illustrate the scale of FASD and the need for action. Such estimates are further used to underpin public health messaging, particularly, in this context, concerning messages relating to alcohol and pregnancy. | Currently the vast mismatch between prevalence estimates and diagnoses is deemed within the source guidance to be an indication of the failure to identify: no consideration is given to alternative explanations, including that prevalence estimates are deeply flawed and should be interpreted with caution.  FASD prevalence is based on estimates of alcohol consumption in pregnancy which often do not and are unable to establish at what gestation alcohol was consumed and in what quantity. The relationship between light to moderate alcohol consumption in pregnancy and negative outcomes is not currently substantiated: there is no convincing evidence of adverse effects at low to moderate levels of consumption. This means it is not surprising that already flawed estimates of the prevalence of alcohol consumption in pregnancy do not result in diagnoses of FASD.  The SIGN guidelines reference a FASD prevalence figure of 32.4 per 1,000 but it is not clear how the authors reached this figure as it does not appear in the studies it references.  Emphasised within the other source documentation and increasingly within public health messaging of the findings by McQuire et al, who calculated that up to 17% of the population are affected by FASD. However the methods used to reach this figure have been roundly criticised. The study is not deemed to be an appropriate indicator of FASD within a UK population. | There is little recent data on alcohol consumption in pregnancy at different gestational bands. SCOPE study data from 2004 found only a third of women drank in the second trimester, and of those that did 96% drank 2 units per week or less,  A recent survey by bpas, conducted by Censuswide in September and October 2019 among 250 women who had been pregnant in the last 2 years (since the CMO’s abstinence only approach to alcohol in pregnancy was introduced) found 80% did not drink at all in pregnancy, 11% stopped drinking as soon as they found out they were pregnant, and the remaining 9% drank at very low levels.  Expert response to the McQuire study (children of women who drank during pregnancy in the early 1990s within the ALSPAC study):  <https://www.sciencemediacentre.org/expert-reaction-to-screening-study-on-uk-prevalence-of-fetal-alcohol-spectrum-disorders-fasd/>  *eg Professor Jean Golding.*  **Prof Jean Golding, Emeritus Professor of Paediatric and Perinatal Epidemiology, University of Bristol and founder of the ALSPAC study, said:**  “The authors of this study have created a screening tool with the aim of identifying children with the fetal alcohol spectrum disorder. They have used very detailed and complex data collected from their pregnancies until the children were 15 years old and developed an algorithm to identify affected children.  “However, there is no hard evidence given that this algorithm works. The women had to have drunk some alcohol in pregnancy for their children to be considered; the algorithm then took account of the presence of reduced growth, behaviour, mental and/or motor development to come to a conclusion that the child was adversely affected by the mother having drunk alcohol in pregnancy. This might be appropriate if the authors had shown that using this algorithm among children of women who had not drunk alcohol in pregnancy revealed a very much smaller proportion of affected children. As it stands, this study cannot be considered to provide an appropriate indicator of the incidence of the fetal alcohol effects.” |
|  | British Pregnancy Advisory Service | Diagnostic criteria (particularly concerning PAE) as included within SIGN guidelines. | We are concerned that the lack of a lower threshold for alcohol consumption in order to make a diagnosis in the absence of sentinel features has no basis in evidence. | The SIGN guideline is the principle source document. Its authors drew on Canadian guidelines which recommend that a diagnosis of FASD can be reached without sentinel features when there is evidence of impairment in 3 neurodevelopmental domains with PAE AT A LEVEL KNOWN TO BE ASSOCIATED WITH NEURODEVELOPMENTAL EFFECTS. However, this qualification has been removed from the SIGN guideline in order to achieve consistency “with the UK CMO advice for no safe level of alcohol consumption during pregnancy”. Yet there is no convincing evidence of adverse effects at low to moderate levels of alcohol consumption and the CMO guidance was changed not on the basis of new evidence of harm as there was and remains none, but on the basis that an exploratory focus group with some new mothers undertaken by the University of Sheffield (unpublished) suggested that some women may have viewed the previous guidelines on low risk alcohol consumption as “a recommendation to drink alcohol at low levels in pregnancy, which was not the intention”.  The fact that it is now proposed that FASD be diagnosed without a lower threshold on the basis that CMO guidelines recommend women are advised to avoid alcohol in pregnancy illustrates the challenges and longer term consequences when guidelines are divorced from evidence. | Please see here for information about how and why the CMO guidelines on alcohol in pregnancy were changed (p12)  <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/545739/GDG_report-Jan2016.pdf>  see also for example:  Mamluk L, Edwards HB, Savović J, et al. Low alcohol consumption and pregnancy and childhood outcomes: time to change guidelines indicating apparently ‘safe’ levels of alcohol during pregnancy? A systematic review and meta-analyses. BMJ Open 2017;7:e015410. doi: 10.1136/bmjopen-2016-015410  Henderson J1, Gray R, Brocklehurst P.Systematic review of effects of low-moderate prenatal alcohol exposure on pregnancy outcome. BJOG. 2007 Mar;114(3):243-52. Epub 2007 Jan 12 |
|  | British Pregnancy Advisory Service | Greater consideration of the consequences of an expansion of diagnostic criteria | We are concerned about the implications of the proposed expansion of diagnostic criteria. In particular:   1. Implications for women of vastly expanded diagnostic criteria, which mean they would be held accountable for neurological harm to their child because of any alcohol consumption in pregnancy. 2. Implications to individuals of vastly expanded diagnostic criteria for FASD. 3. Implications for services of vastly expanded diagnostic criteria. | A major expansion of the criteria under which diagnosis would be made could have a severe impact on women and their families, without any assurance of an improvement in care available. Children who are currently diagnosed with ASD with or without ADHD, where there are 3 areas of neurological impairment, could be diagnosed with FASD under the SIGN criteria. Holding women’s behaviour in pregnancy accountable for neurological outcomes in the absence of any evidence that alcohol influenced her child’s impairment is deeply problematic.  The diagnostic criteria represent a reversal of causation. The effect of widening the definition of FASD is in essence to reverse the process of causality. Rather than evidence being sought that proves a causal relationship between any alcohol In pregnancy and impairments, the existence impairments where a mother consumed alcohol in pregnancy is now deemed to be the result of that behaviour. |  |
|  | CoramBAAF | Assessment and access to diagnostic services are available via clear pathways of care, in all areas of England.  Agreed diagnostic criteria and terminology.  Care pathway and diagnostic criteria to include those children where there is missing or unknown information regarding alcohol exposure in pregnancy. | Specific interventions / support are available for children/ YP with FASD so diagnosis confers benefit.  Prevention of secondary problems in circumstances where children/young people are not assessed or have a long wait for assessment this can include both physical and mental health complications. | Terminology confusion, lack of clarity re diagnostic criteria and diagnostic services required have left many children and families with inappropriate assessment and support historically |  |
|  | CoramBAAF | Policy/Engagement with health/social care/education colleagues/ commissioners on the diagnostic value of FASD | - FASD is a diagnosis in its own right with a specific profile of need which should be considered in the overall SEND profile and in the commissioning of services  Services should be commissioned and integrated within neurodevelopmental paediatric services | Historical lack of commissioner engagement in planning diagnostic and support services. |  |
|  | DHSC | Improving commissioning and diagnostics | To improve health outcomes, we would like to see improvements in commissioning of services to improve the speed of diagnosis of FASD in the health and care system. Once diagnosed, improvements should be made to offer individuals and families with the appropriate support and care. |  |  |
|  | East Herts and Area FASD Support Network | Access to diagnosis | Using the low-end estimate of the screening prevalence study done by the University of Bristol more than 300 children might be born each yearborn each year in the Trust area are born with FASD. Actual diagnoses are a tiny fraction of that figure and this underlines the need for commissioning of diagnostic services for FASD as without this nothing else is possible. There is also a need for automatic assessment for the 428 co-morbid conditions that have been associated with FASD as part of the diagnostic process. Looked After Children should all be screened for FASD | The East and North Herts Trust has instructed its paediatricians to refuse referrals for diagnosis of Foetal Alcohol Spectrum Disorders (FASD). The Clinical Commissioning Groups (CCGs) in East and North Herts, and surrounding areas, commission no services specifically for FASD. For Looked After and Adopted Children rates of FASD are thought to be higher than for the general population, necessitating a greater focus on screening and diagnosis in this cohort. | Identified as a priority by stakeholders, members of the East Herts and Area FASD Support Network, at a meeting held on September 21, 2019 to discuss this submission. Further evidence comes from correspondence with the East and North Herts Trust; the East and North Herts CCG from Support Network members and with local MPs. It also comes from discussions with Trust staff, and from Freedom of Information Act requests to all Trusts and CCGs in the region. Further evidence comes from direct experience of parents and carers in attempting to gain access to diagnosis over the past few years.  Also from the FASD UK Alliance Survey that can be found at: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | East Herts and Area FASD Support Network | Create a Care Pathway/Access to Services | Parents/carers are often asked to accept an autism diagnosis to ensure at least some access to services, although these may be inappropriate and even damaging. There is a need for a clear care pathway to a post-diagnostic protocol for FASD and its co-morbid condition because, with early diagnosis and such access, the prognosis for those with the condition can be good. Without it, risks to physical and mental health, of secondary disabilities, drug or alcohol addiction, prison and even early death multiply. | With extremely restricted access to diagnosis in our Support Group area, it is unsurprising that there is no clear pathway for care and therapeutic services, and that no specific services related to FASD exist. To be effective, this care pathway must include access to paediatrician as an overall care manager, occupational therapy, physical therapy, speech and language therapy, services related to co-morbid condition with a specialist with understanding of FASD, access to mental health services and therapeutic counselling appropriate to a person with FASD; a consistent protocol for medications; all this should be achieved within specified time frame. | Identified as a priority by stakeholders, members of the East Herts and Area FASD Support Network, at a meeting held on September 21, 2019 to discuss this submission. Further evidence for this need is drawn from direct contact with the NHS Trust in our support group area, and with specialist services to which support group families have been referred. It is drawn from the experiences of the families in the support group, and from learning drawn for discussions with families in the FASD UK online support group, as well as family experience of best practice in other countries, particularly Canada.  Also from the FASD UK Alliance Survey that can be found at: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | East Herts and Area FASD Support Network | FASD should be recognised as a lifelong neurodevelopmental disorder | Without this recognition access to services is harder. Some, such as as PALMS in Hertfordshire require a diagnosis of autism and/or a learning disability before providing specialised psychological counselling and support for families. Children with FASD but without a learning disability could definitely benefit from PALMS’ services but cannot access them as children with autism but no learning disability can do. | Stakeholders are denied access to key services because their neurodevelopmental disability is not recognised by the NHS as being worthy of access to services. | Identified as a priority by stakeholders, members of the East Herts and Area FASD Support Network, at a meeting held on September 21, 2019 to discuss this submission. Also drawn from the experiences of group members attempting to access services unsuccessfully.  Also from the FASD UK Alliance Survey that can be found at: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | Evelina London Community Services | Early identification training and diagnostic pathways should exist regarding FASD. The role of clinical genetics should be clarified and include ethical considerations. Workforce training in child health is needed. | There is evidence that earlier identification enables more targeted support and may reduce risk of further harms through missed educational, developmental and mental health interventions | There is a current gap in both training and in the service offers to this cohort | SIGN guidelines (2019) Guideline 156: Children and young people exposed prenatally to alcohol - Full guideline.  BMA Board of Science Guide for Professionals (2007) <http://www.nofas-uk.org/PDF/BMA%20REPORT%204%20JUNE%202007.pdf> |
|  | Evelina London Community Services | Understanding implications for children and families | There is a lack of evidence base around impacts of diagnosis on children and families including in relation to stigma and family relationships and functioning  Participatory work should be prioritised with children and the national baseline offer should factor this in | Whilst charities such as NOFAS have produced participatory work with children, there is a lack of wider recognition around implications and engagement in service design | SIGN guideline 156 (2019)  Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) – conditions and interventions A systematic review and assessment of the social, medical, economic and ethical aspects. Swedish Council on Technology Assessment in Health Care (2016) ["How could I have done this?" Thoughts of mothers of children with fetal alcohol syndrome](http://www.scie-socialcareonline.org.uk/how-could-i-have-done-this-thoughts-of-mothers-of-children-with-fetal-alcohol-syndrome/r/a1C0f0000066j4lEAA) Source: [SCIE Social Care Online](https://www.evidence.nhs.uk/search?om=%5B%7B%22srn%22:%5B%22SCIE%20Social%20Care%20Online%22%5D%7D%5D&ps=50&q=fetal+alcohol+syndrome&sp=on) - 01 January 2017 - Publisher: Taylor and Francis  Larcher V, Brierley JFetal alcohol syndrome (FAS) and fetal alcohol spectrum disorder (FASD)—diagnosis and moral policing; an ethical dilemma for *paediatriciansArchives of Disease in Childhood* 2014;99:969-970. |
|  | FASD Awareness South East | Every NHS Trust to have a policy AND pathway on the identification and assessment of individuals at risk of FASD | This is important to reduce the distress to families and individuals, reduce the possibility of secondary mental health issues occurring through delayed diagnosis and late intervention, which in turn costs the public purse more than required if diagnosed and supported earlier | Without this pathway and the information gathered, many children will end up in the care system with behaviours and health conditions that are unexplained and could have been avoided. Their needs are not able to be recognised and supported because the evidence isn’t in place to get the correct diagnosis and support. |  |
|  | FASD Greater Manchester | A clear pathway for diagnosis | There is no pathway in our local area and across the country there is a post code lottery. There is evidence that early diagnosis of any disability results in better outcomes | This is a key area due to the impact on children and young people and their families. Without a diagnosis this can greatly impact on the outcomes of young people and can result in breakdown of families, as they don’t receive the correct support. Without a diagnosis often the wrong support and interventions are forced on families as they are seen as difficult if they don’t take part. This can have a detrimental effect on all involved and also cause secondary difficulties. | We are a small group, but we listen to the needs of our local families, so we know what support they need. This is also one of the biggest areas of discussion on FASD UK face book page, which is run by the FASD Alliance and has over 2400 members  NOFAS UK - A crisis of commissioning  It is clear from NOFAS UK Hear our voices that the impact this has on all involved.  NHS website says early treatment and support can help limit the impact on an affected child’s life |
|  | FASD Greater Manchester | Mental Health support | Due to the current lack of support and how people with FASD don’t seem to meet the current criteria for mental health support, this is important to make sure they have access. | This is a key area for support because mental health difficulties are a secondary condition of FASD. Often people are not receiving any support or incorrect support, so this increases their chances of mental health difficulties. Often mental health practitioners do not have the correct training. So, they don’t know what intervention to do or they don’t understand the persons needs so cannot effectively work with the person and often results in detrimental results | All our views come from listen to children and adults with FASD and their families. We have also meet with our Local children and adult’s mental health team (CAMHS) and other professionals to discuss these issues |
|  | FASD Greater Manchester | Support awaiting and after diagnosis | For the best possible outcomes for children and adults with FASD and their families | Upon receive a diagnosis, families are often given no or little information. They are often not signposted to any support, so it can be several years of struggling before they find the correct information or support. This means family have often gone through struggles that could have been avoided. Also, the mental health of family members can be greatly affected by caring for these individuals without support and can result in break down in families and ill health of family members who’s needs are often forgotten. Without this being include resources will often not be available and currently it is often done at the expenses of individual families who want to help others. | All our views come from listening to children and adults with FASD and their families. Our families often talk about what it was like before they found our support group and how much better it is having people to talk to who understand. They have spoken about people saying you have to parent differently, but know one tell you what that means. They find it supportive to know they are not alone, and others are having the same difficulties and we can all share ideas and resources. |
|  | FASD Network UK | Screening and diagnostic provision that is local, timely, holistic & multidisciplinary and available across the lifespan. | Too many of our families have been told that they cannot have a diagnosis locally as there is no one trained to diagnose it or there are concerns around the stigma of the diagnosis.  The majority of families have been challenged and asked why they were ‘pushing so hard to label their child with FASD’. Families have the lived experience of FASD and aren’t seeking to label but to gain a clinical diagnosis much like those with other neuro disabilities do. Diagnosis helps them to understand the child and informs their parenting strategies that may have greater success. Diagnosis helps the child understand themselves when they are realising that they aren’t like their peers. It aids with accessing provision such as finding a suitable school, EHCP’s, therapy, disability services, blue badges, DLA, respite care, mental health provision, transport, medication etc. To gain holistic services it starts with a clear recognition of the condition which starts with a diagnosis.  Children who are older who get their diagnosis are often experiencing greater challenges and poorer outcomes from lack of ongoing understanding of their condition and early intervention.  We know many children who have aged into adulthood without ever being screened or able to get their diagnosis. Currently it is almost an impossibility to get a diagnosis as an adult as the most common diagnostic pathway is through paediatrics. The adults who missed their FASD diagnosis often get diagnosed with Borderline Personality Disorder so the NICE guidance around BPD needs to be understood through the lens of FASD too. Thahns study identified reduced life expectancy for those with FASD.  Children with complex behavioural presentations are often guided through the CAMHS pathway but CAMHS is not commissioned to diagnose or support FASD so typically looks at ADHD or ASD instead. If CAHMS are not looking at FASD as a comorbidity then the health and wellbeing of the child is potentially compromised. If they are diagnosing ADHD or ASD without an understanding of FASD then they may also incorrectly diagnose the key condition and simply diagnose the secondary conditions instead.  Incomplete diagnoses also have implications for medications. Many of our children have reactions to the medications given to them because their FASD was not recognised. | We have children with multiple medical issues that are not being holistically addressed. Popova’s study highlights over 400 conditions triggered by prenatal alcohol exposure. There is no one key coordinator overseeing the physical, cognitive and behavioural needs of children so families are dealing with multiple practitioners who have largely no understanding of FASD and whom families consistently have to train.  Streissguth 1999 highlighted protective factors for the best long term outcomes which included a diagnosis before aged 6.  Many of our families have had to go out of area and pay privately for a diagnosis which has increased their debt and poverty levels. Consistently those private assessments have been rejected by local practitioners as it was a private assessment. Families should not have to pay for a private assessment that should be free on the NHS like autism and other neurodevelopmental conditions are.  From feedback, very few of our fostering families have ever had a LAC medical that has actively touched on or investigated the possibility of FASD during a medical. (See reference to guidance which suggests active investigation). Here is a system which could and should actively screen for FASD but fails to consistently do so. Implementation of screening could address the significant delays and poor signposting to diagnosis and support.  Gregory’s UK study in 2015 identified that 34% of LAC children had prenatal alcohol exposure which suggests that proactive screening and attentive monitoring of that exposure is essential to aid early intervention and to prevent delays in diagnosis.  The best first service our families report has often been the Health Visitor role in triggering SaLT, OT and Portage (Portage is regarded as excellent). These initial services often lay down the first evidence of neuro developmental concerns which get people into supportive services and onto diagnostic pathways more smoothly. | Popova et al Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis.  The Lancet, 2016; DOI:  [10.1016/S0140-6736(15)01345-8](http://dx.doi.org/10.1016/S0140-6736(15)01345-8)  Borderline Personality Disorder  <https://www.nice.org.uk/guidance/cg78>  Streissguth, A., Barr, H., Kogan, J., and Bookstein, F. (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE*): Final Report. Seattle, WA: University Washington School of Medicine, Dept. of Psychiatry and Behavioral Science, Fetal Alcohol and Drugs Unit.  Reduced life expectancy of those with FASD  <https://www.ncbi.nlm.nih.gov/pubmed/26962962>  **The guidance for medicals for Looked After Children. Point 44**. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/413368/Promoting_the_health_and_well-being_of_looked-after_children.pdf>  Gregory 2015 <https://journals.sagepub.com/doi/abs/10.1177/0308575915594985> |
|  | FASD Network UK | Access to existing neurodevelopmental and mental health services that are commissioned for parallel conditions ie autism, ADHD, such as those traditionally operated by CAMHS and a range of external therapeutic providers. | There are standardised pathways for ADHD and Autism and although there are issues (delays) with the provision of these services, there is a recognisable multi-disciplinary pathway (MAAT teams) that could be utilised in terms of SaLT, OT, Psych, medical evaluations. The training of those teams in FASD will be crucial if they are to expand their remit to include FASD.  We go into CAMHS teams to train and find that there is little to no expertise in this topic so it would be clinically unsound to use CAHMS as a diagnostic and therapeutic vehicle at the current time. There is scope to develop that option in the future if it would mean there is a one doorway system that also accepts children with FASD.  Early onset self-harm, anxiety, child to parent violence and addictions is evidenced in many of our families. The CAHMS referrals have often been declined due to the child being ‘too complex’ or ‘has a disability not a mental health condition’ or have addictions so ‘addictions must be addressed before we can work with them’. They cannot access LD CAMHS as the majority have an IQ that is too high even at IQ71 or IQ72 which is just above the cut-off point. The lack of engagement or the anxiety in our children can make it hard to attend appointments which often results in removal from the programme before it has really got started. Children with FASD will require longer to benefit therapeutically from provision and they are typically pro-social and dislike change so the continuously cancelled appointments and changes of staff further impede the engagement from our young people.  Some families have never had a full neurodevelopmental assessment. Some have assessments at the point of diagnosis and there was no system to update this at regular intervals. At minimum, a full medical and cognitive and adaptive functioning assessment would be welcomed at key transition points ie starting school, transferring to high school, transferring to leaving care team/college etc so that support plans can target the needs and strengths identified. The majority of young people who transfer from child to adult services, fail to get a service to meet their needs. There is a great deal of concern over the transition from child to adult services. | The standard offer for behavioural presentations are often CBT based which are frequently ineffective and alternative options are rarely available. There has been a lot of positive feedback from families about equine therapy, art therapy, music therapy, sensory integration therapy etc so a range of creative therapeutic approaches needs to be available.  Occupational Therapy – This is extremely highly regarded by families with children with FASD and is considered an essential service but it is a struggle to access on the NHS as they are often tied in to Autism teams which children with FASD cannot access. The service secured privately is often high quality and less time restricted but beyond the budget of many families.  Speech and Language - This is hard to access on the NHS as the majority of our children with FASD talk relatively well and mask their lack of understanding. Private assessments or assessments for the EHCP process consistently report low receptive language skills and slower auditory processing. Expressive language, whilst superficially good, lacks depth of understanding. It often highlights the lack of social understanding and cues. This is valuable information to adjust educational support and strategies but is denied many due to lack of access.  Educational Psychology  Frequently they are declined for children with FASD as they are viewed through the lens of ‘making progress so there is no need for an EP’, ‘naughty’ and ‘refusing to do the work’ rather than struggling with learning. It is only if they qualify for an EHCP (this is hard to obtain without a fight and particularly if there is no diagnosis) that the true levels of need are often identified. We have seen young people entering their final year of high school suddenly being recognised as having a learning disability with an IQ under 70 who have been seen through the lens of SEMH and behavioural issues rather than a core cognitive impairment than impacts on learning and regulating behaviour. | There are NICE guidelines for related topics which do not include FASD but do include a mention of Autism. This use of diagnostic specific language is a barrier to accessing services and therapies which may be helpful. NICE needs to consider replacing the term Autism with Neuro-developmental Conditions (or other generic terminology) which would aid access for a number of parallel conditions.  <https://pathways.nice.org.uk/pathways/transition-from-childrens-to-adults-services> |
|  | Greater Manchester Health and Social Care Partnership | Diagnostic pathway in place (children and adults) in all CCG areas with maximum waiting time of 6 months | With an accurate diagnosis, families and individuals are able to understand the challenges they face and put strategies in place.  This also prevents money being wasted on inappropriate use of medications and clinical time. | Timely and local access to diagnosis. |  |
|  | Greater Manchester Health and Social Care Partnership | Everybody who is diagnosed with FASD should be able to access support appropriate for their individual needs | FASD affects everybody differently. With the right support and adjustments people can manage better. |  |  |
|  | National Organisation for Foetal Alcohol Syndrome-UK | Pathway for diagnosis and support | A clear pathway will help more people with FASD receive the diagnosis and support they deserve | Despite Government statements that CCGs are responsible for commissioning services for FASD this is simply not happening. | See “A Crisis of Commissioning: CCGs are Failing Government Policy on FASD,” NOFAS-UK. <http://www.nofas-uk.org/WP/wp-content/uploads/2019/05/A-Crisis-of-Commissioning-report-FINAL.pdf>  An easy read version is here: <http://www.nofas-uk.org/?p=1301>  The BMA report (2017) recommends, “Action is required to improve the provision of services and referral pathways for the diagnosis, management and support of people affected by prenatal alcohol exposure. Individuals affected by prenatal alcohol exposure often go without a diagnosis, or are mis-diagnosed, and there are no frameworks for the clinical management of those with FASD in the UK.” <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy> |
|  | National Organisation for Foetal Alcohol Syndrome-UK | Recognition of FASD as lifelong neurodevelopmental disorder | People with FASD should have access to neurodevelopmental services  People with FASD need to access appropriate adult services, it is not just an issue for paediatric services.  The successful transition to adult services needs to begin while still in children and adolescent services by appropriately trained staff. | People with FASD who don’t have a learning disability are denied access to neurodevelopmental services, which are however open to those with autism who do not have a learning disability. | Stakeholders report lack of services for transitioning into adulthood. See for example, “Hear Our Voices,” <http://www.nofas-uk.org/WP/wp-content/uploads/2018/05/HearOurVoicesPublication_FINAL2_ForWebsite.pdf>  See also “5 key areas for quality improvement,” The FASD UK Alliance, 8 October 2019. Available: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | Neurological Alliance | Support for Adults and Mental Health provision. | Research on FASD and mental health proves high rates of suicide and depression. Impulsive behaviour is due to problems with executive brain function that has been damaged by alcohol. This leads to poor decision making, financial budgeting and organisational skills.  Many adults with FASD are in the Youth Justice system.  Females with FASD are exploited sexually or “diagnosed” as bad parents and children put in care. High incidence of substance abuse/ addictions due to impulsivity and mental health issues.  Brain damage leads to inability to function age appropriately, especially with self-care activities. FASD children may present as verbally articulate which gives the impression that the person has full capacity but chooses not to comply. FASD memory impairment is another issue that is grossly misunderstood but impacts on a person’s ability to manage everyday life as a child or adult.  There must be a transition process put in place during the final year at school between CAMHS and Adult services. |  | <https://bmjopen.bmj.com/content/8/2/e0196>  [www.proofalliance.org](http://www.proofalliance.org)  <https://www.researchgate.net/publication/323205445> |
|  | Neurological Alliance | Diagnosis/ Assessment/ Identification | There needs to be National pathway for diagnosis for children and adults. Currently, one national expert in Surrey. Adoptive parents forced to pay privately because of lack of professional understanding. Too big an assumption that all FASD is diagnosed by a Paediatrician.  There must be Regional specialists and specialist centres with induction training for students, GP’s, CAMHS, and Paediatricians.  Can we diagnose in the uterus? If so we need to introduce this in antenatal care.  Can we screen all new born babies? We test for Cystic Fibrosis which occurs 1/4000 births.  Research suggests FASD occurs at rate of 8/1000. It is the leading cause of Learning disability so the impact is enormous on both parents and life-long costs to society. FASD does not necessarily have facial features but will still have brain damage.  Early diagnosis would allow for early intervention this could prevent family breakdown especially Fostered/ Adoptive placements or a kinship carer such as a grandparent becoming unwell through the stress of the caring role. Provide all caregivers with knowledge and skills to manage difficult behaviours and sensory processing difficulties to prevent deterioration in mental health and overload in the primary caregiver. FASD is not considered in any post adoption plan so families struggle to comprehend what is happening.  Medical training must include FASD as GP’s think that if a child has any genetic mutations or reasonable growth that they can’t also have FASD but this is not true. |  | ‘Adoption Today’ publication  <http://www.fasdnetwork.org>  The Care Act 2014 |
|  | Royal College of Paediatrics and Child Health | Educational support and assessment of additional needs. | If infants are known to be at risk for FASD, subsequent educational and behavioural difficulties could be screened for at a pre-school age. Failing this, awareness from staff in these settings of the risk of these problems. | Early, targeted help with educational needs as and when they are identified. | NICE guideline NG72 – Risk and prevalence of developmental problems and disorders. Whilst this applies more directly to preterm infants, the evidence and risk for behavioural and executive functioning disorders would be directly applicable to the FASD population. |
|  | Royal College of Paediatrics and Child Health | Involvement of Clinical Genetics Speciality | Many children with suspected FAS are referred to Clinical Genetics re. dysmorphology & potential differential diagnoses. | Not to discount an important stakeholder & thus provide a more comprehensive/balanced overview. | Please see Fetal Alcohol Syndrome & Other Embryopathy section of review article: Arch Dis Child 2016;101:581–584 [attached] |
|  | Royal College of Paediatrics and Child Health | Early confirmation and habilitation for hearing loss. | There is evidence that amongst the comorbidities found in fetal alcohol spectrum disorder (FASD), both sensorineural hearing loss and conductive hearing loss are found with a higher prevalence in children with FASD than in the general population. | Confirmation and early habilitation of a sensorineural hearing loss results in better speech and language and social development. Recurrent serious otitis media as the cause of the conductive hearing loss is found commonly amongst these children who can benefit from management according to the NICE Guidelines for otitis media with effusion. | Popova S, Lange S, Shield K, Mihic A, Chudley AE, Mukherjee RA, Bekmuradov D, Rehm J. Comorbidity of feta alcohol spectrum disorder: a systematic review and meta-analysis. Lancet 2016: 387; 978 – 87.  Church MW, Eldis F, Blakley BW, Bawle EV. Hearing, language, speech, vestibular and dentofacial disorders in fetal alcohol syndrome Alcoholism: Clin and Exp Res Apr 1997: 21(2); 272 – 237.  3Cone-Wesson B. Prenatal alcohol and cocaine exposure: influences on speech. J of Communication Disorders 2005: 38; 279 – 302.  <https://cks.nice.org.uk/otitis-media-with-effusion#!scenario> |
|  | Royal College of Paediatrics and Child Health | Habilitation for listening difficulties | Amongst children with FASD, listening difficulties with and without a hearing loss are also very prevalent. | These difficulties impinge on a child’s social and educational development which eventually impinge on life function. | McLaughlin SA, Thorne JC, Jirikowick T, Waddington T, Lee AKC, Hemmingway SJA. Listening difficulties in children with fetal alcohol spectrum disorders: more than a problem of audibility. J of Speech, Language and Hearing Research 2019: 62; (1532 -1548) |
|  | Royal College of Paediatrics and Child Health | Testing for subtle difficulties with balance | Although research did not reveal huge vestibular difficulties, children with FASD did show evidence of difficulties with balance when deprived of their somatosensory and visual input. It is thought therefore that some children do have deficits in the vestibular system. | With several comorbidities found in these children, difficulties are compounded even though any one difficulty may be small. Addressing each difficulty, including deficits in the vestibular system, if this is confirmed, could improve their life function as a whole. | Roebuck TM, Simmons RW, Mattson SN, Riley EP. Prenatal exposure to alcohol affects the ability to maintain postural balance Alcoholism: Clin and Exp Res Feb 1998: 22(1); 252 – 258.  Roebuck TM, Simmons RW, Richardson C, Mattson SN, Riley EP. Neuromuscular responses to disturbance of balance in children with prenatal exposure to alcohol. |
|  | Royal College of Speech and Language Therapists | All people suspected of having or affected by fetal alcohol spectrum disorder should have a thorough speech, language and communication assessment carried out by a speech and language therapist. | The presence of speech, language and communication (SLC) disorders in children with pre-natal alcohol exposure and/or FASD is well documented in research (Hendricks et al 2019; McGee et al., 2009, Wyper & Rasmussen, 2011). FASD is prevalent in looked-after children yet due to difficulties accessing diagnostic information (such as alcohol consumption by birth-parents) they are often undiagnosed or diagnosed much later in childhood (Bakhireva et al. 2018). Looked after children, unsurprisingly are also a group where there is typically high rates of SLC disorders (McCool & Stevens, 2011). Furthermore, there are considerable links with FASD, SLC difficulties and youth justice (Kippin et al 2018; Bower et al 2018). Early identification of SLC will support delivery of early intervention and monitoring, which may have long-term positive consequences on the individuals and the state alike (Garrison et al., 2019). | Only a small percentage of children with FASD are identified in the UK (Howlett et al. 2019). Of those with FASD, Alcohol-related neurodevelopmental disorder is the most common subtype (McQuire et al 2019). FASD can be commonly misdiagnosed as other neurodevelopmental disorders as symptoms overlap. FASD can present in children through delayed receptive and expressive language as well as difficulties with social communication (Hendricks et al. 2019), all typically associated with Autistic spectrum disorder (ASD). Speech and language therapists are pivotal to the assessment of both of these conditions and are uniquely positioned to evaluate the nuanced and subtle differences between the communication profiles of both types of children. | The RCSLT undertook a research priorities setting project for learning disabilities and several questions pertaining to foetal alcohol syndrome and speech, language and communication were identified. These were:  Typical presentation of speech, language and communication skills in people with foetal alcohol syndrome and learning disabilities  Impact of communication difficulties experienced by children with foetal alcohol syndrome and learning disabilities on a) quality of life and b) educational attainment, compared to children with typically developing language profiles  The impact of using Video Interaction Guidance in SLT compared to non-video feedback programmes for a) people with learning disabilities and b) people with learning disabilities and foetal alcohol syndrome in terms of the individual’s perceived level of communication competence |
|  | SCM1 | Routine FASD assessment for all looked after and adopted children | Children who are in the looked after system and/or placed for adoption who have not been exposed to alcohol in utero are in the minority. Some recent statistics show that conservatively 75% of this group of vulnerable children and young people have been exposed to alcohol in utero. | These children are amongst the most vulnerable in society and they are faced with a life ahead of them with brain damage that nobody knows about or acknowledges and it is dangerous to them and to our society. The outcome in life would be totally different if this was addressed as routine and the financial impact on services for the duration of their lives would also be very different. |  |
|  | SCM1 | FASD to be recognised as a neurodevelopmental disability | FASD is a life -long diagnosis, in the same way that a diagnosis of Autism is life-long. It is a neurodevelopmental disability and needs to be classified as such and as being life- long at diagnosis. | People with FASD need to be able to access a pathway of care in the same way that anyone else with a neurodevelopmental disability can. FASD is an invisible disability and in my opinion, because of this it is more difficult to live with than a visible disability. It is vital that it is recognised as such |  |
|  | SCM2 | Children with FASD should have access to the services and assessment from professionals who can identify the neurocognitive impairments | Children with FASD do need assessments by professionals who work in a collaborative manner to identify their impairments. | Assessment of children for FASD requires multidisciplinary assessment by Medical professional, Psychologists, Speech and Language Therapists and possibly occupational therapists. Children who have not had required specialists assessments may not have their cognitive impairments identified. | Looked After Children and young people-QS31  The National Organisation for Foetal Alcohol Syndrome-UK (2019) [A crisis of commissioning: CCGs are failing government policy on FASD](http://www.nofas-uk.org/?cat=44)  Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html) |
|  | SCM2 | Improved recognition of children with FASD by health professionals | Children with FASD do tend to have delay in diagnosis due to lack of recognition of their symptoms and profile by health professionals | Recognition of the profile of children with FASD will enable them access the right level of interventions in schools and the community | British Medical Association (2016) [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy)  Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html) |
|  | SCM2 | Clear guidance on the criteria for making diagnosis of FASD in at risk children in England and Wales | There is a need to prevent under recognition of FASD in children who have had exposure to maternal alcohol consumption but do not have sentinel facial features | Children with FAS facial features are more likely to be recognised and diagnosed however they are in the minority and majority of the children exposed to maternal alcohol do not have the facial features but do have the neurocognitive impairment. These children do need to have access to comprehensive assessments and the relevant interventions. | Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html)  British Medical Association (2016) [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy) |
|  | SCM2 | Children with history of maternal alcohol exposure during pregnancy should have comprehensive neurodevelopmental assessment. | Children exposed to maternal alcohol use during pregnancy may present with developmental delay and neurodevelopmental difficulties. | Early detection of children with developmental difficulties as a result of maternal alcohol use will result in support and interventions being put in place at home and school. Outcome for children is generally better with early intervention | [Developmental follow-up of children and young people born preterm](https://www.nice.org.uk/guidance/qs169) (2018) NICE quality standard 169  Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html) |
|  | SCM3 | Improved equity in access to FASD diagnosis | Location of available services – currently limited to two clinics nationally. Lack of knowledge proves a barrier to accurate and timely referral pathways.  The assessment and diagnosis of FASD can help the individual, their family, and service providers  to understand the challenges associated with a lifelong disability that requires accommodations and supports to maximise success –SIGN 156. | A lack of knowledge and understanding of FASD among healthcare professionals means they often  may not feel competent to carry out an assessment and make an appropriate diagnosis. Variation in knowledge and awareness poses a significant challenge to the implementation of a comprehensive and consistent approach to the management of FASD. – SIGN 156  Consideration given to diagnostic criteria for individuals of different ages from neonatal to adulthood. | Refer to existing SIGN 156 guidance and expertise from QS committee expert. |
|  | SCM3 | Adequate support for families with AEP or awaiting diagnosis | Process of referral, assessment and diagnosis may be time consuming even with improved pathways. SIGN guidance - noted the potential for assessment or diagnosis to cause anxiety and stigma and emphasised that the process should be undertaken with sensitivity. | Clear information, support and signposting will enhance journey of individual and family from point of neurological/developmental concerns through to assessment and diagnosis.  This is in view of both the ongoing holistic challenges faced by the individual awaiting assessment and any additional anxieties faced with the diagnostic process. | Refer to existing SIGN 156 guidance and expertise from QS committee expert and lay members for lived experience. |
|  | SCM3 | Post-diagnosis support | Integration into universal services.  Quality of life and support for people diagnosed with FASD and their families. | Consideration given to individualised support needs for individuals of different ages from neonatal to adulthood and their families. | Refer to existing SIGN 156 guidance and expertise from QS committee expert and lay members for lived experience. |
|  | SCM4 | All commissioners should ensure that there is a pathway for all children who are referred  This will need to include provision for access to a clinical psychologist for expert assessment | Existence of such pathways is very patchy and even non-existent in many areas, causing patients affected to have a challenging, long and tortuous journey in obtaining the correct diagnosis. |  | See experience of Scottish FASD network in providing a network of paediatricians and support for diagnosis. |
|  | SCM4 | The pregnancy alcohol history and the possibility of Fetal Alcohol Spectrum Disorders should be considered in all children who are referred for neuro-developmental assessment or assessment of behavioural disorders.  [This recommendation affects Child Development Centres, CAMHS, and Educational services]  ? in terms of excluded populations – should include correctional institutions and prison population and Courts |  |  | This is not currently the case!  There is good experience of teaching packages provided for the criminal justice service in Oregon, Canada and Queensland, Australia |
|  | SCM4 | Ongoing help and support are provided to children and their families and adults with a diagnosis of FASD, appropriate to their needs | Some from charity and family support groups and some form |  | Interventions available in other countries (eg Canada: CanFASD).  Some intervention work in progress currently in the UK. |
|  | SCM5 | All Children and adults have access to local and where not available specialist FASD assessment and diagnosis | People with possible FASD are not supported to get referral for evaluation and processes not available. Specialist MDT limited yet it is known the recognition due to the complexity of presentation, the differing phenotype and wide neurodevelopmental overlap needs experts alongside generalists to deliver this as described in BMA Board of science review | There is a real barrier to accessing services and establishing services. Professionals have limited knowledge and families struggle to get help. The complex nature of the fASD presentation does not help this. Developing proper pathways supported by expertise is vital to establish to ensure a large group of individuals with lifelong health needs are not missing our on care | FASD APPG. Initial report of the inquiry into the current picture of FASD in the UK today. London; 2015.  NOFASUK. A crisis of comissioning. London: NOFAS UK; 2019.  SIGN. SIGN 156. Edinburgh: Health improvement Scotland; 2018.  BMA Board of Science. Fetal Alcohol Spectrum Disorders, a guide for healthcare practitioners update. London; 2016  Popova S, Lange, S., Shield, K., Mihic, A., Chudley,A.E., Mukherjee, R.A.S., Bekmuradov, D., Rehm, J. Comorbidity of fetal alcohol spectrum disorders: a suystematic review and meta-analysis. Lancet. 2016;387:978- 87.  Kable JA, Mukherjee, R.A.S.,. Neurodevelopmental disorders associated with prenatal exposure to alcohol (ND-PAE): A proposed diagnostic method of capturing the neurocognitive phenotype of FASD. European Journal of Medical Genetics. 2016.  Morleo M, Woolfall K, Dedman D, Mukherjee RAS, Bellis MA, Cook PA. Under-reporting of Fetal Alcohol Spectrum Disorders: an analysis of Hospital Episode Statistics. BMC Paediatrics. 2011;14(11):1-6.  Mukherjee RAS, Layton M, Yacoub E, Turk JT. Autism and autistic traits in people exposed to heavy prenatal alcohol:data from a clinical series of 21 individuals and a nested case control study. Advances in Mental Health and Intellectual Disability. 2011;5:43-9  Mukherjee RAS, Wray E, Commers M, Hollins S, Curfs L. The impact of raising a child with FASD upon carers: findings from a mixed methodology study in the UK. Journal of Adoption anf Fostering. 2013;37(1):43-56.  Suttie M, Foroud T, Wetherill L, Jacobson JL, Molteno CD, Meintjes EM, et al. Facial Dysmorphism Across the Fetal Alcohol Spectrum. Pediatrics. 2013;131(3):e779-e88.  Mukherjee RAS, Wray E, Curfs L, Hollins S. Knowledge and opinions of professional groups concerning FASD in the UK. Journal of Adoption anf Fostering. 2015;39:212-24.  McQuire C, Mukherjee R, Hurt L, Higgins A, Greene G, Farewell D, et al. Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study. Preventive Medicine. 2019;118:344-51 |
|  | SCM5 | All cases suspected as high risk of alcohol exposure are followed up for early signs of neurodevelopmental difficulties until adulthood | There is evidence that individuals with FASD do not present at the same period therefore those identified as high risk should have follow up to allow intervention early | Children at risk may or may not develop a disorder and it is not sometime clear until they have been challenge in an area of function they struggle with. As such following people up is vital to allow early diagnosis and reduce impact more widely | BMA BoS. Fetal Alcohol Spectrum Disorders, a guide for healthcare practitioners update. London; 2016 2016.  Scholin L, Watson J, Dyson J, Smith L. Alcohol Guidelines for pregnant women. London: Institute of alcohol studies; 2019.  Mukherjee RAS, Wray E, Curfs L, Hollins S. Knowledge and opinions of professional groups concerning FASD in the UK. Journal of Adoption anf Fostering. 2015;39:212-24.  Mukherjee, R.A.S., (2015) FASD for Paediatricians: Paediatrics and Child Health: |
|  | SCM5 | Post Diagnostic support and treatment is offered to all diagnosed with FASD based on developing and established evidence base. | Once diagnosed there is a lack of support to help families access ongoing care and a lack of knowledge of FASD in other groups means that people are not supported and inappropriately blamed for things that are often actually related to the condition and not the situation | To prevent secondary impacts and to reduce the finaicnal burder overall longer term it is vital familes are supported and educated how to work better with these children and adults | SIGN. SIGN 156. Edinburgh: Health improvement Scotland; 2018.  Young S, Absoud M, Blackburn C, Branney P, Colley B, Farrag E, et al. Guidelines for identification and treatment of individuals with attention deficit/hyperactivity disorder and associated fetal alcohol spectrum disorders based upon expert consensus. BMC Psychiatry. 2016;16(1):324.  BMA BoS. Fetal Alcohol Spectrum Disorders, a guide for healthcare practitioners update. London; 2016 2016.  Mukherjee RAS, Wray E, Commers M, Hollins S, Curfs L. The impact of raising a child with FASD upon carers: findings from a mixed methodology study in the UK. Journal of Adoption anf Fostering. 2013;37(1):43-56.  FASD A. Initial report of the inquiry into the current picture of FASD in the UK today. London; 2015.  NOFASUK. A crisis of comissioning. London: NOFAS UK; 2019. |
|  | SCM6 | Access to timely diagnosis for those with suspected FASD | Early diagnosis can help put in place proper support, preventing secondary impact on mental health and wellbeing  Particular attention should be paid to Looked After Children and those who are adopted | Access to diagnosis is currently at best a post-code lottery in England.  The rates of FASD are higher in the LAC/adopted population | Government recognises the importance – see for example: “Early intervention services can help reduce some of the effects of FASD and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups.” Steve Brine, MP, then Parliamentary Under-Secretary for Health, Written question – 139045, 27 April 2018  See for example NOFAS-UK, “A Crisis of Commissioning: CCGs are Failing Government Policy on FASD” <http://www.nofas-uk.org/WP/wp-content/uploads/2019/05/A-Crisis-of-Commissioning-report-FINAL.pdf>  Geraldine Gregory, Venkat Reddy, Clare Young, “Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis,” Adoption and Fostering, September 28, 2015, <https://journals.sagepub.com/doi/abs/10.1177/0308575915594985> |
|  | SCM6 | Pathway is needed for diagnosis and support | A ‘post-code lottery’ currently exists for services | Stakeholders report wildly varying experiences when seeking diagnosis and post-diagnostic services.  CCGs report a lack of pathways and services | See “A Crisis of Commissioning”  See “Hear Our Voices: FASD Stakeholders Share Their Experiences with Policy Makers,” <https://fasduk.files.wordpress.com/2019/10/hearourvoicespublication_final2_forwebsite.pdf> |
|  | SCM7 | Treatment and Support: 5. Access to Diagnosis of FASD within 6 months of referral by a service, within reasonable travel distance of an individual’s home, and support for families with a child who are waiting for a diagnosis or have received a diagnosis of FASD. |  |  |  |
|  | SCM8 | Diagnosis and follow up for alcohol exposed babies and children | Follow up for the baby at developmental milestones by a specialist paediatrician would streamline care and referral for diagnosis at a later date.  The diagnostic process should include a family, social and medical history as well as complete physical examination.  Additional support from specialist health visitors. | It is critical that FASD is recognised as a physical, behavioural and neurodevelopmental health condition. Family history must be reviewed and, if possible, a three-generation family tree obtained. This allows the team to identify existing developmental disorders in the family and identify the potential for inheritable disorders, based on an occurrence in the parents, siblings or second- or third generation relatives. Consanguinity in the parents may indicate a risk of certain inherited disorders. The presence of FASD in other siblings is a risk factor for having another affected child. | SIGN, Young people and Children  exposed to alcohol.  <https://www.sign.ac.uk/assets/sign156.pdf>  The National Organisation for Foetal  Alcohol Syndrome-UK (2019) A crisis of  commissioning: CCGs are failing  government policy on  FASD <http://www.nofas-uk.org/?cat=44> |
|  | TACT | Easier diagnostic routes to identify children who have a Foetal Alcohol Spectrum Disorder | There needs to be clearer, and more accessible, diagnostic routes, with medically aware staff (notably Health Visitors’, General Practitioners’; Paediatricians) able to diagnose in order to ensure that parents and carers have access to the support the children require | Many foster carers – and presumably birth parents also - are met with medical ignorance and without that they struggle to get the support and understanding the require |  |
|  | Royal College of Nursing | Assessment and management | We welcome the focus by NICE on this important topic which is a growing issue for practitioners. This is evident in the recently published Scottish Intercollegiate Guidelines Network (SIGN) and various NICE guidance including guidance on child development, antenatal, postnatal and alcohol related issues. | SIGN guidance found that exposure to alcohol during pregnancy can result in other fetal injuries and that its wider effects, along with fetal alcohol syndrome contribute to conditions and behavioural disabilities that are associated with prenatal exposure to alcohol, labelled as Fetal Alcohol Spectrum Disorder. Practitioners need high quality standards to improve the assessment and management of this disorder. | Scottish Intercollegiate Guidelines Network (2019) [Children and young people exposed prenatally to alcohol](https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html)  [Developmental follow-up of children and young people born preterm](https://www.nice.org.uk/guidance/qs169) (2018) NICE quality standard 169  [Antenatal and postnatal mental health](https://www.nice.org.uk/guidance/qs115/) (2016) NICE quality standard 115 |
|  | SCM1 | A pathway of care/treatment/ support created | To ensure a positive outcome in life for children and young people with FASD. Also, to support professionals who are diagnosing. Currently, in most of the UK, if you are lucky enough to get a diagnosis that’s the end of it. No pathway to follow and that is terrifying for children, young people and their parents and carers. | A pathway needs to be created in order to guide the professionals involved with children and young people with FASD because there is nothing at all in place currently. This is resulting in services, particularly CAMHS being overloaded with cases that shouldn’t really sit with them and who they are unable to deal with and help appropriately. |  |

| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **Management and follow up** | | | | | |
|  | Adoption UK | Access to relevant post-diagnosis support (including in the home, educational, mental health, access-to-work etc.) for people with FASD and those caring for them/close to them (including support groups and advice line, information and signposting, training etc.) | People with FASD may require support at any point in their lives to help them cope with the challenges that the condition may present. | There is a distinct lack of statutory support being delivered for those affected by FASD. As the SIGN guidelines point out, a lack of intervention and support will mean these individuals are more likely to perform poorly in education, develop mental health problems, and become addicted to drugs and alcohol. A failure to intervene will lead to negative outcomes specifically for those living with FASD, but also for society more generally. Therefore, the state has a duty to deliver support services which help those with FASD to prosper and avert these social issues | In June 2019, Adoption UK in Scotland launched its FASD Hub, funded by Scottish Government. The new service provides information, support and training to those parents and carers of children and young people with FASD, and professionals working with these families. <https://www.adoptionuk.org/fasd-hub-scotland>  The UK has the fourth highest level of prenatal alcohol use in the world and a 2018 UK based study showed up to 17% of children screened had symptoms consistent with FASD. <https://www.bristol.ac.uk/news/2018/november/first-uk-prevalence-estimate-fasd.html>  The lifetime cost for one individual with Foetal Alcohol Syndrome (FAS) in 2002 was estimated to be $2 million. This is an average for people with FAS and does not include data on people with other FASD diagnoses. People with severe problems, such as profound intellectual disability, have much higher costs. <https://www.cdc.gov/ncbddd/fasd/data.html> |
|  | British Medical Association | A framework for the clinical management of individuals affected by the range of FASDs should be developed and adequately resourced throughout the UK. | Effective clinical management requires the implementation of postnatal interventions and the cooperation between a wide range of healthcare professionals.  The lack of a framework currently is a barrier to this. | There are no frameworks for the clinical management of FASD in the UK – and research is limited. | Please see the BMA’s 2007 report, updated in February 2016 on [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy). |
|  | CoramBAAF | Children /YP / adults with FASD and their parents and carers are able to access appropriate support and interventions. | To improve outcomes in areas of physical and mental health, education, social inclusion and equality. |  |  |
|  | East Herts and Area FASD Support Network | Put the H into EHCP  (Education and Healthcare Plan) | EHCPs run until a child has reached the age of 25, they are supposed to bridge the gap between childhood and adulthood. They are supposed to ensure that both health and education need are being met. Health needs are rarely included in an EHCP, meaning that health related aspects enabling access to education are often ignored. This can particularly impact the mental health of young people with FASD, impacting their ability to learn. | Paediatricians managing care are not given the time necessary to input into the drafting of EHCPs. Educational psychologists are not, for the most part, trained in FASD. SENCOs do not understand the condition and are unable to obtain information from doctors about it. Therapists working in schools such as Occupational or Speech and Language Therapists need training in FASD. | Identified as a priority by stakeholders, members of the East Herts and Area FASD Support Network, at a meeting held on September 21, 2019 to discuss this submission. Also drawn from the experiences of group members in drawing up EHCPs for their children with schools.  Also from the FASD UK Alliance Survey that can be found at: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | Evelina London Community Services | Care pathways should be in place with clear evidence-based standards | Given the scale of the estimated prevalence (up tp 17%), child health practitioners in primary, secondary and tertiary care should be aware of and be able to deliver an offer to this cohort in terms of evidence-based interventions and rights- based access to services. | There is a gap in terms of management pathways for these children within the UK. Knowledge around specific therapeutic interventions which may optimise function and support outcomes should be clearly identified and provided. | SIGN guideline 156 (2019)  [Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: a population-based birth-cohort study](https://www.sciencedirect.com/science/article/pii/S0091743518303323?via%3Dihub) Preventive Medicine (2018) Cheryl McQuire, Raja Mukherjee, Lisa Hurt, Andrea Higgins, Giles Greene, Daniel Farewell, Alison Kemp, Shantini Paranjothy.  BPSU surveillance report- due after November 2019 for prevalence data |
|  | FASD Network UK | Post diagnostic support pathways and systems that are multi-agency and FASD informed in their approach | Significant numbers of families have been refused a diagnosis and were advised that this was due to there being no formal post diagnostic pathway so it was deemed unethical to diagnose.  Many hundreds of my local families who are lucky enough to have been able to access a diagnosis through their local paediatrician (postcode lottery) do not get ongoing clinical support. They are often immediately signed off by the paediatrician.  Clinicians in the areas where there is local paediatric expertise will often signpost to FASD Network UK to provide information, support and services to families. As a voluntary sector organisation, we are not funded or commissioned in any way to provide this support but through self-funded means and peer efforts will provide a peer service to meet the needs of the family and work in a way that facilitates access to education, health and social care provision. (There was a recent funding pot announced for FASD but we are ineligible for it despite being one of the largest organisations for FASD families. The criteria needs revisiting).  Most medications for conditions is via CAMHS oversight. We have families who cannot get medications for their children because they are not on the books of CAMHS and some of those medications can be as simple as melatonin to aid sleep which is a common issue for many with FASD. | The postcode lottery for diagnosis and post diagnostic support and indeed support for those prenatally exposed but undiagnosed needs to be addressed.  Over the past decade FASD Network UK has seen higher rates of caregiver stress and higher level service needs from those who have received no formal diagnosis and aftercare service compared to those who get a best practice though informal models of care.  When families access multi-agency assessments and support plans then both the child and the family have higher levels of resilience and a greater ability to advocate well for additional services.  With correct early intervention and support, we see an increase in positive outcomes for those families in terms of progress in school, towards employment and in terms of mental health and wellbeing.  Families would like an annual review by trained clinicians to ensure that the health and wellbeing is optimised and any potential new services may be considered and referrals made for emerging symptoms. | <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>  <https://pathways.nice.org.uk/pathways/autism-spectrum-disorder>  <https://pathways.nice.org.uk/pathways/attention-deficit-hyperactivity-disorder>  <https://pathways.nice.org.uk/pathways/antisocial-behaviour-and-conduct-disorders-in-children-and-young-people>  <https://pathways.nice.org.uk/pathways/learning-disabilities-and-behaviour-that-challenges> |
|  | Neurological Alliance | Support for families with “Disabled Child” | Many children with FASD will look normal but as such have a hidden disability. Without a diagnosis, other resources cannot be accessed. Criteria to access support needs to be made equitable.  There is a postcode lottery.    Families need clear care pathways, education programmes on behaviour management, obsessions and communications.  Research shows that caring for a child with FASD is even more difficult than caring for a child with Autism. Families need respite care on the care pathway which could be in the home and outside of it to prevent ill health of carers or family breakdown. There is a high incidence of anxiety and depression amongst parent carers.  Parents need to be identified as Carers in their own right due to many years of disturbed financial support, where adoptive parents often give up well paid professional careers to meet the needs of their children. There must be ring-fenced, designated post-adoption support, children placed with diagnosis confirmed and parents given training to develop skills to cope with challenges. | For too long the issue of FASD has been kept behind closed doors because of the false reporting that has gone on in adoption and fostering services to get the process through.  Public services default position is to blame the parents or kinship carers for poor parenting. This must stop and the diverse range of carers must be acknowledged. | The Care Act 2014 |

| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **Additional areas** | | | | | |
|  | Adoption UK | Knowledge and education of professionals (medical and other e.g. education, criminal justice and social work professionals) likely to be working with people with FASD. | Medical professionals obviously play a significant role in identification, assessment and diagnosis of individuals with FASD. Additionally, a range of other professionals will work with and support people with FASD. Therefore, knowledge and understanding of the condition is not just relevant to those in the medical profession. | Various studies have shown there is shortfall in awareness, understanding and knowledge of FASD among medical and clinical professionals.  Education is a major challenge for many children with FASD but it isn’t classified as a spectrum disorder like ASD, for example. This means children with the condition are often not receiving additional support like others with additional needs. No reasonable adjustments will be made these children and as a result school will be a hostile environment in which they are less likely to prosper. | NOFAS-UK’s GP ‘check-up’ also indicated that GPs need more education and guidance on issues related to FASD and the life-long impact of the brain damage and other health and learning issues that can result from prenatal exposure to alcohol. Among the findings, only 31% of the GPs said they had in-depth education regarding FASD. Around half said it should be more thoroughly taught in medical school.  More than a third of midwives had seen an infant with FAS. The advice given to pregnant mothers by participants varied. The midwives stated that they would like more information and support.  Winstone, A. M. & Verity, C. (2015) “Antenatal alcohol exposure: An East Anglian study of midwives’ knowledge and practice”, British Medical Journal. <https://doi.org/10.12968/bjom.2015.23.3.180>  Respondents to Adoption UK’s Adoption Barometer (2019) told us that FASD is not well-understood by health and education professionals. |
|  | DHSC | Education and awareness of FASD | Improve the education and training for health and care professionals and other professionals that will have a role/interaction dealing with pregnant women and children, so they are aware of FASD as a health impact. |  |  |
|  | East Herts and Area FASD Support Network | Training and Education for medical and other NHS personnel | Without educated and properly trained GPs, specialist, nurses and therapists, diagnosis and care for people with FASD is impossible. Without properly trained GPs and midwives, prevention education is impossible to deliver. Without adequate understanding of the scale and scope of FASD, there is no recognition even that services are needed and that some standard services need to be provided in a tailored well to allow access by people with condition. There is uneven access to services. Families and individuals living with FASD report a constant need with almost all NHS staff to provide information about the existence of the condition, about its symptoms and the accommodations needed to allow people with the condition to access services. | Families living with FASD in the East and North Herts NHS Trust and surrounding areas find it almost impossible to find GPs that have knowledge and understanding of the condition; and the same is true of consultants as well as other NHS staff. Well trained doctors, nurses and therapists would significantly improve services available and the ability of people with FASD to access those services. With education and training the provision of specialised services including prevention, diagnosis and post-diagnostic care for people with FASD will be impossible. There is no protocol for medications for people with FASD, for example in the management of ADHD. | Identified as a priority by stakeholders, members of the East Herts and Area FASD Support Network, at a meeting held on September 21, 2019 to discuss this submission. Their knowledge and experience comes from first hand knowledge of dealing with the NHS. Freedom of Information requests have also shown that Trusts in the Support Group area provide no training or education for their staff on FASD.  Also from the FASD UK Alliance Survey that can be found at: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | FASD Awareness South East | Specific, standardised, quality-assured mandatory training for all midwifery staff | Midwifery staff need to be trained on how to take a useful alcohol and lifestyle history from a pregnant woman that will be used throughout the life of each affected individual to evidence the impact of alcohol consumption on their lives | Midwifery staff need to be trained to use this information to give them the tools to support and signpost each family effectively. Expectant parents are rarely asked about their alcohol consumption pre pregnancy and during pregnancy. Support for prospective fathers and partners to understand and support their pregnant partner to be included. | Just one example of the effects of the paternal parent’s alcohol consumption on a baby: <https://journals.sagepub.com/doi/full/10.1177/2047487319874530> |
|  | FASD Awareness South East | Multi-agency training for health and social services to include health visitors, portage and looked after nurses | To ensure they understand the policy and pathway on the identification and assessment of individuals at risk and/or presenting indicators of FASD. | It’s imperative that all agencies work together to be able to support individuals pre-pregnancy, during pregnancy and after birth for the best possible outcomes |  |
|  | FASD Greater Manchester | Training | Again, there is a postcode lottery of professionals with training, with very few across all areas of Health, social care and education. | Without a proper plan to train all professionals involved with Children and Adults who have FASD, things will not improve. Their needs will not be address and their outcomes will be greatly impacted, this will result in secondary condition and increasing costs. | All our views come from listening to children and adults with FASD and their families. We have also meet with our Local professionals to discuss these issues and they have also expressed a need for training. |
|  | FASD Network UK | Training of all practitioners across health, education, social care, mental health and justice fields delivered by those with lived experiences of FASD. | We have been providing bespoke FASD training to professionals across all fields for many years and each session we see a lack of knowledge that the condition even exists amongst professionals. Every training session people ask why they have not heard about FASD before. The fact that FASD Network UK has training provided by those with lived experience makes a massive impact on the delegates and is repeatedly flagged as a key strength of the session. This is of key importance as the work and training on FASD expands in the UK.  Families are going to practitioners across all fields who have no understanding about FASD and they have to repeatedly teach practitioners about it so that they can try and get a service or support for their child. This is an unacceptable level of service.  Parenting courses (Triple P, Solihull, Magic 123, PBS etc are NOT working for families of children with complex needs and should not be part of the pathway). These courses seem to have been rolled out to multi-agency professionals as a tool of choice for parents of children whose behaviour challenges. Specialist parenting courses for children with disabilities are much more successful and welcomed by families. Specialist de-escalation training is needed for the majority of families whose children have volatile responses to stressful situations. We consistently find that courses led by FASD experienced trainers are valued highly by families | If families get services then it is often according to caregiver status (fostering, adoption, kinship, birth) rather than according to individual need which is illogical and discriminatory. Our birth families and kinship families are the least likely to get services.  Adoption Support Fund is still largely focusing on attachment therapy despite the fact that many families are living with a child with FASD and need the holistic therapeutic approaches that take into account the whole presentation of the child.  Foster carers can find it hard to advocate for a child with whom they have no Parental Rights especially if they have a social worker who is untrained in FASD and cannot comprehend the family perspective on what needs to be addressed. All social workers need compulsory training in FASD especially considering the high prevalence in the LAC population.  Many families are going through safeguarding investigations for behaviours typically associated with FASD (ie confabulation) and families have been questioned about actions that never happened or were misunderstood due to lack of practitioner training. This is very dangerous. Whilst there is compulsory safeguarding training by LSCB’s, it does not address safeguarding risks associated with FASD. In those areas where we have worked closely with safeguarding teams, children and families with FASD are better understood and risks of false allegations are reduced. |  |
|  | Greater Manchester Health and Social Care Partnership | Mandatory training for all midwives on Chief Medical Officers Guidelines, alcohol harm in pregnancy, alcohol screening in pregnancy and delivering brief alcohol interventions | Recent research found that only 51% of midwives knew the CMO guidelines | Midwives need to be giving women the correct and consistent messaging.  Midwives need to be skilled in assessing alcohol use in pregnancy and giving | ‘Alcohol guidelines for pregnant women: Barriers and enablers for midwives to deliver advice’ is available to view via the following link: <http://bit.ly/alcmidwives>.  Barry, K. L., Caetano, R., Chang, G., DeJoseph, M. C., Miller, L. A., O’Connor, M. J., Olson, H. C., Floyd, R. L., Weber, M. K., DeStefano, F., Dolina, S., Leeks, K. (2009). Reducing alcohol-exposed pregnancies: A report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects. USA: Centers for Disease Control and Prevention.  O’Connor, M. J., & Whaley, S. E. (2007). Brief intervention for alcohol use by pregnant women. American Journal of Public Health, 97(2), 252-258. |
|  | Greater Manchester Health and Social Care Partnership | Mandatory FASD awareness training for education, health & social care and criminal justice workforce | Professionals on the whole do not know about or understand FASD. As a consequence, individuals with FASD are not being diagnosed or are misdiagnosed. They are not receiving the right support and are often punished because of their disability |  |  |
|  | National Organisation for Foetal Alcohol Syndrome-UK | Training for professionals | Properly trained health and social care professionals can help prevent FASD and through proper diagnosis and support they can help people with FASD live better lives and avoid devastating and costly secondary conditions | At the moment there is no consistent training provided across or within professions.  This may be facilitated in part through an establishment of an intercollegiate and expert committee that could explore how FASD is covered in the relevant academic programmes across professions as occurred alongside/as a spin-off of the domestic violence Quality Standard process?  Proper training can ensure that women receive appropriate counselling and support if they have had an alcohol-exposed pregnancy. | NOFAS-UK receives frequent requests for training – there is a gap out there.  A small NOFAS-UK survey in 2017 of 150 GPs indicated cause for concern. For ex, only approximately one-quarter of the GPs identified alcohol in pregnancy as having greater long-term risks to the baby than other substances such as heroin, crack, or smoking. More than two-thirds of the GPs indicated that facial features were present in 50% or more of those with an FASD (of those 11% said facial features were present in 100%) – in fact this number is believed to be <10%. For more information see: <http://www.nofas-uk.org/?p=804>  NOFAS-UK has provided training and resources for midwives and student midwives (reaching more than 16,000). But there is still a great need for more materials and an eagerness for updated information. The latest report from the Institute for Alcohol Studies showed that “four out of ten midwives were not aware of the actual content of the 2016 alcohol guidelines on pregnancy.” <http://www.ias.org.uk/News/2019/16-September-2019-Midwives-call-for-more-support-to-deliver-alcohol-advice.aspx>  Stakeholders identified training for professionals as the highest priority to improve their own wellbeing. See for example Appendix G (70% of parents/caregivers) and also Appendix H (100% of a small sample of those with FASD). <https://tinyurl.com/FASDUKAlliance-5Areas4NICE>  NOFAS-UK receives calls from women who do not understand what FASD is, what the nature of the risk might be if a pregnancy was alcohol-exposed and how with proper support people with FASD can lead positive lives and contribute to society in many ways. |
|  | Neurological Alliance | Education systems | All teachers need educating on FASD and the impact on learning skills, not just SEN staff. Most of these children will be struggling in main-stream provision. Must be allocated an Education Healthcare Professional. Need investment in SEN provision, not enough places to meet national need.  Children and families need support not judgement. Schools need to be able to focus on the child not just “exam results”. Current ethos is not child centred and penalises rather than supports the child. Children with FASD need to be in smaller classes and taught, with regular underpinning of life skills that they will struggle with because of brain damage. Children with FASD need early intervention from occupational therapists for sensory integration and life skills. Children need school staff that understand sensory overload and can be flexible within timetable to meet needs, eg Sensory breaks.  Mental health needs and emotional regulation must be supported by school. Children return home and ‘explode’ due to management failures at school. School break times are unstructured and FASD children need to be supported appropriately, simply keeping children indoors does not help. | There is a huge element of prevention that can be put into education services to reduce the damage to education attainment and subsequent social withdrawal and depression. These children feel failed and watch their parents be failed by a system that does not understand their needs.  Parents need consistency and collaboration with a multi-disciplinary approach between education, CAMHS and social services working with parents, not against them.  Little recognition in the system that FASD is an organic brain injury with mental health co-morbidities that is life-long. | See data for children with SEN exclusions |
|  | Northumbria Healthcare Foundation NHS Trust | Additional developmental areas of emergent practice | Training is required for all professionals working with children and substance misuse services to raise awareness of the link between PAE and the risk of FASD.  The risks of alcohol in pregnancy and FASD should be core curriculum for all pre-registration health professionals, teachers and social workers. | Training should address some potentially challenging issues including health professional’s attitudes towards alcohol; and how to support women who have already consumed alcohol in pregnancy. |  |
|  | SCM1 | All Paediatricians to be trained on how to diagnose FASD correctly | Too few doctors in the UK know how to diagnose FASD and too many of those that do focus on a requirement for the ‘typical’ facial features for a diagnosis. These facial features happen in a tiny percentage of cases and this way of thinking is outdated but still adhered to. This means that currently only a tiny percentage of children on the FASD spectrum are being diagnosed with this life -long brain damage. | The life outcome/expectancy for a child who received a timely diagnosis of FASD is completely different to a child who didn’t. Early intervention with support is key. When a child with FASD is not diagnosed then comorbid conditions will occur, predominantly mental health conditions. This results in young people and adults with FASD needing access to NHS services for conditions that only exist as a direct result of either a lack of diagnosis at all, or a diagnosis that came too late. |  |
|  | SCM6 | Training of health and social care professionals about FASD | Under-trained or misinformed practitioners can delay for prolonged periods access to appropriate support and care – or at times squander valuable time and resources on inappropriate therapies and support. | Stakeholders report a lack of understanding about diagnostic criteria among professionals – misinformed practitioners (who for example believe certain facial features are required for diagnosis) can often either misdiagnose or delay diagnosis for years.  When FASD is unrecognised or misunderstood the wrong therapies and strategies can lead to deepening problems rather than helping. | In a recent survey of 450 parents/caregivers of those with FASD, more than 70% identified better training for professionals as the #1 thing that would improve their own wellbeing. (See appendix G, p 35 in FASD UK Alliance, “5 key areas for quality improvement which you consider as having the greatest potential to improve the quality of care for FASD,” 8 October 2019. Available: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | SCM7 | Prevention: Wider workforce training in alcohol exposed pregnancies and FASD for services who come in contact with women who are 16 to 44, sexual active, using alcohol and not using an effective form of contraception. |  |  |  |
|  | SCM7 | Prevention: Up to date mandatory education for all midwives in the CMO guidance, risks of alcohol exposure to the unborn and FASD |  |  |  |
|  | SCM8 | Training and education for health care professionals | A lack of knowledge and understanding of FASD among healthcare professionals means they often may not feel competent to carry out an assessment and make an appropriate diagnosis. Variation in knowledge and awareness poses a significant challenge to the implementation of a comprehensive and consistent approach | Specialist health care professionals in midwifery and health visiting should implemented. the said staff can then deliver training to peers so that consistent advice is provided. Specialist support differs between Trusts and localities | NICE Pregnancy and social complex factors in pregnancy.  <https://www.nice.org.uk/guidance/cg110> |
|  | TACT | More awareness for professionals working with foetally affected children who are in care | At present Foetal Alcohol Spectrum Disorders are not included in any professional training courses (Social Work; Teaching; Foster Carers) and this needs to be addressed.  Social Work in particular (the area I am most familiar with) has virtually zero knowledge of Foetal Alcohol Spectrum Disorders and consequently “labels” children who have behavioural or emotional issues with other labels with which they are more familiar | Many – perhaps between 30% and 60% - of the children in the care system are foetally affected. (And between 6% and 17% of whole population)  In the absence of knowledge of Foetal Alcohol Spectrum Disorders, many children are viewed as having “attachment issues”; Attention Deficit Hyperactivity Disorder; “affected by trauma” ……or just plain “naughty” or the result of “poor parenting” resulting in many children being in care inappropriately | Research by Dr Cheryl McQuire at Bristol University (published Nov 2018) |
|  | Adoption UK | The five priority areas which have been outlined above should be part of a wider national FASD strategy covering prevention, diagnosis and support, with accompanying implementation plans and resources. |  | For the above areas, and other aspects such as prevention and public health messaging, to be improved then an overarching national strategy is required to tie these areas together. | Studies such as the *Adoption Barometer* and *Crisis in Commissioning* have highlighted the postcode lottery in support for those living with FASD or caring for someone with FASD. A major benefit of a national strategy is that it will facilitate the standardisation of a basic statutory offer of FASD support services. Without a national strategy which outlines what constitutes a basic offer of support, this postcode lottery in support will continue. |
|  | FASD Awareness South East | FASD must be recognised as a lifelong disability for which there is no cure and will impact on the affected individual throughout their lives | A clear understanding of FASD and its cause, conditions and effects must cover all professional areas, so there is a consistency and prevention of incorrect diagnosis. Early intervention therapies and support aimed at minimising the impact of FASD on affected individuals, and management issues—including access to appropriate community care and support services. | Awareness must feature in the post graduate training of all doctors, nurses, psychologists and other health care workers. All CCG should be able to demonstrate compliance with this. At a recent local school/ community conference, a member of the CAHMS team was asked what they knew about FASD. They said they didn’t know anything about it. “Is it real?”, came the response. |  |
|  | SCM6 | FASD should be recognised as a neurodevelopmental disorder | Without this recognition, people with FASD who do not have a learning disability are denied access to services, such as those defined for people with “learning disabilities and autism” | Stakeholders report being denied access to those services available to other neurodevelopmental disorders such as autism, especially if the person with FASD does not have a learning disability. | See for example: “5 key areas for quality improvement which you consider as having the greatest potential to improve the quality of care for FASD,” Feedback from more than 300 families for the NICE Quality Standard on FASD Consultation, The FASD UK Alliance, 8 October 2019. Available: <https://tinyurl.com/FASDUKAlliance-5Areas4NICE> |
|  | Evelina London Community Services | Public health and lobbying for alcohol industry regulation | Effectiveness linked to current public health policy must be evidenced and strategies revised and invested in. Public Health and RCPCH have a duty to address this politically |  |  |
|  | British Medical Association | Diagnostic guidelines for FASD (fetal alcohol spectrum disorders) should be developed. | The range of FASD are commonly under diagnosed reflecting a number of factors including; a lack of a specific diagnostic test; an under-reporting of maternal alcohol consumption, or lack of maternal alcohol history; differing and poorly defined diagnostic criteria for FASD; and a lack of multidisciplinary neurodevelopment teams to complete comprehensive assessments needed to evaluate the full range of FASD. | In the UK there are no formal FASD diagnostic guidelines.  Variation in knowledge and awareness of FASD poses a significant challenge to the implementation of a comprehensive and consistent approach to diagnosis and management of  The BMA supports an approach that would see guidelines that have been developed in Canada, adopted in the UK. | Please see the BMA’s 2007 report, updated in February 2016 on [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy).  Please see the 2005 Canadian guideline, updated in 2016, [Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan](https://www.cmaj.ca/content/188/3/191) |
|  | British Medical Association | Guidance should be developed on the implementation of targeted interventions and referral to specialist alcohol services for women at high-risk of prenatal alcohol exposure. | There is evidence related to the effectiveness of selective prevention strategies targeting high risk or pregnant women. | There is no specific UK guidance on the delivery of targeted prevention for ‘at-risk’ women. | Please see the BMA’s 2007 report, updated in February 2016 on [Alcohol and pregnancy: preventing and managing fetal alcohol spectrum disorders](https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy). |
|  | FASD Network UK | There is no need to recreate a brand new wheel or process for FASD. NICE guidance exists across a number of completely related fields but needs to either include the language and condition of FASD or remove the labelling of one condition ie Autism to allow services to flow to all neuro-developmental conditions equally. These changes will enable access to the commissioning of support services for all our children and families and adults with FASD across their lifespan to improve life chances and health and wellbeing, irrespective of their geographical base, their income level or indeed whether they are care experienced or living at home with their families. This consultation has the opportunity to make a difference that lasts a lifetime so is one to be considered carefully, listening to the voices of the families and those currently supporting them. |  |  |  |
|  | SCM6 | Meconium testing? | This is not widely used but an area of development. If newborns were routinely tested and the results noted this might aid in later diagnosis of FASD. | This would have to be handled carefully in a non-judgmental climate and with supportive care around both the mother and child. Noting in the child’s file that a positive meconium sample was present at birth could provide proof of an alcohol exposed pregnancy if the child were later exhibiting symptoms - though clearly there are limits (e.g. - it doesn’t show exposure throughout the entire pregnancy so a negative would not mean there was no exposure). | “Use of meconium FAEE revealed tenfold more cases of heavy exposure to maternal drinking than did maternal reports.” “Prevalence of Fetal Alcohol Exposure by Analysis of Meconium Fatty Acid Ethyl Esters; A National Canadian Study,” Kaitlyn Delano, Gideon Koren, Martin Zack & Bhushan M. Kapur, Scientific Reports volume 9, Article number: 2298 (2019)  <https://www.nature.com/articles/s41598-019-38856-5> |
|  | SCM5 | Better parenting interventions  Better treatment pathways |  |  |  |
|  | DHSC | Addressing harms from alcohol | To reduce the harmful impact of alcohol on individuals who already experience harm, we expect to see improvements in identifying individuals at or could be at risk of alcohol harm and provide support and interventions to help them and reduce future FASD related births. |  |  |
|  | Public Health England | Having a child with FASD is a strong predictor of subsequent alcohol-exposed pregnancies and women who are alcohol dependent during pregnancy should be supported to access appropriate sexual health services including the offer of long acting reversible contraception. |  |  | See The causal web of foetal alcohol spectrum disorders: a review and causal diagram. This can be viewed at: <https://link.springer.com/article/10.1007/s00787-018-1264-3>. |
|  | SCM7 | Prevention: Access to LARC at the point of request (Labor wars, Substance Misuse Services, Women’s centres) |  |  |  |
|  | Adoption UK | FASD recognised as a lifelong disability, with continuity of care for young people with FASD transitioning to adult services. | Children with FASD become adults with FASD and will face many of the same challenges as they transition into adulthood. Therefore, it is important support does not fall away once they reach this point. | Like with mental health services and other aspects of social care, the transition to adult services can be problematic. There is a general lack of empathy/interest where adults with FASD are concerned. The fact damaged is done in the womb and the child is born with the condition means that the focus has tended to be on babies and small children, overlooking the fact they will become adults with FASD. | A recent FASD Alliance survey in relation to this consultation asked respondents to identify the five priority areas which require improvement for those with FASD or suspected FASD. Nearly two-thirds selected ‘FASD recognised as lifelong disability’ while more than a third selected ‘ensuring continuity of care for young people with FASD entering adult services’.  A common criticism of the SIGN guidelines in Scotland is their failure in recognising the lifelong impact of the condition and properly account for the challenges faced by adults with FASD. This is an area where NICE should look to improve on the SIGN guidelines. |
|  | Evelina London Community Services | Working with partner agencies around parental risk and resilience | Owing to the aetiology, safeguarding and family support should be considered as well as early intervention and preventive strategies within families | There is a gap in specific guidance and knowledge in how to achieve best outcomes for affected children | Working Together to Safeguard Children (2018) <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2> |
|  | FASD Greater Manchester | Coordinator, point of contact across health, social care and education | Continuity of care is important for best outcomes | Families tell us about how they are passed between services as no one knows what to do. Often when they don’t meet criteria for a service, they will be sent to a service they started at and sometimes this could be 2 or 3 time referred to that service. Each time they have to tell the whole story again. Having a coordinator would mean they could ‘Tell it once’ and triage. Then a person centred plan can be made and they can go straight to correct services that are required, after the coordinator holistically looking at the whole situation of these often very complexed individuals. This would be a greater use of resources and reduce waiting times across the services. | All our views come from listening to children and adults with FASD and their families. We have also meet with our Local professionals and discussed the issues about being passed around services and not meeting criteria. our local SEND inspection also discussed the need to ‘tell it once’ |
|  | Public Health England | Developing continuity of carer in maternity and the longitudinal relationship between the family and the health visitor (especially if the child is removed) where the mother is diagnosed as alcohol dependent would increase the safety of the baby and mother and to begin to identify longer term needs where a baby is likely to have FASD. Continuity of health care professional promotes trust and disclosure, helps families navigate multi-agency input and the role of lead professional prevents families and children “getting lost in the system”. In parallel, ensure that a community or developmental paediatrician service is in place. | The most recent analysis of serious case reviews where a child is seriously hurt or killed found that one in three (37%) included parental use alcohol as a factor. Across all cases 41% were where a child was aged under one year at the time of their death, or incident of serious harm; and nearly half of these babies (43%) were under 3 months old. | Please see Pathways to harm, pathways to protection: a triennial analysis of serious case reviews 2011 to 2014. This can be viewed at: <https://www.gov.uk/government/publications/analysis-of-serious-case-reviews-2011-to-2014> |  |
|  | DHSC | Improved data collection | Improve the recording of information and data related to FASD in the health and care system to improve surveillance, support commissioning and tackle inequalities. |  |  |
|  | Northumbria Healthcare Foundation NHS Trust | An annual audit of local maternity notes would ensure compliance and measure data across the country. Data to be published in NMPI reports to collect national alcohol consumption prevalence and referral rates. | This will provide national data intelligence to inform the planning of FASD service provision and identify training needs in maternity and paediatric staff. | Audit could be part of the role of the maternity alcohol champion or specialist midwife.  Alcohol in pregnancy data should be incorporated into NHS quality targets such as the CQC and Maternity Data Set to ensure that the issue is regarded as a priority nationally. |  |
|  | Northumbria Healthcare Foundation NHS Trust | A single format of accurate data collection is required across the NHS. | Consistent and clear data should be collected and documented in designated maternal and neonatal medial notes to facilitate this | We need to unify and utilise existing datasets such as the Maternity Dashboard and Trust Performance Reports to provide invaluable health informatics that can be reliably compared and monitored within each Trust and across the country. |  |

# Appendix 3: Feedback from 300 families to inform the NICE Quality Standard on FASD supplied by the FASD UK Alliance

[The text below is an extract from a document supplied by the FASD UK Alliance to inform the NICE quality standard on FASD. The full document can be found at <https://tinyurl.com/FASDUKAlliance-5Areas4NICE>. It has not been included in this briefing paper for the sake of brevity.]

**About the FASD UK Alliance**

The FASD UK Alliance is a coalition of more than 20 groups working to support those with FASD and their families and to raise awareness of Foetal Alcohol Spectrum Disorders.

We welcome NICE’s efforts to engage stakeholder views in its consideration of a new NICE Quality Standard on FASD. This report shares recent feedback received from across England.

**Introduction**

In many ways the problems highlighted by the survey are inter-related and complex. But the message from respondents is simple. They want FASD as a condition recognised. They want legislative protection and commissioning of services on a scale similar to that provided for autism (not least because FASD is more prevalent than autism). They call for a proper pathway for diagnosis, post-diagnostic care, and wider support to be created and funded properly because FASD is a lifelong neurodevelopmental condition that makes this necessary.

At present individuals and families struggle to access diagnosis, and post-diagnostic care and support. A major reason for this is that medical and other professionals have little or no education or training about FASD, and therefore struggle to recognise it. A negative cycle ensues where because the condition is not known or recognised, services are not available. Clinical Commissioning Groups and Trusts don’t provide services because the need is not identified. This is the cycle that must be broken.

To replace it there is a crying need for a positive cycle, where recognition leads to diagnosis, and that in turn leads to the full range of post-diagnostic care commissioned as standard by CCGs and provided without the current tremendous resistance by Trusts.

There is also a massive need for education about the risks of alcohol consumption in pregnancy and FASD from the NHS for patients. This will need to be complementary to PSHE education in schools and public health messaging. But for the current generation, with at least 6% thought to be affected, the emphasis must be on providing the care they so badly need.

**This Survey**

Over 320 families affected by FASD answered a questionnaire to contribute to this report. Seventy-one per cent are adoptive parents/carers/guardians of a person with FASD, some others are parents of young people with suspected FASD but no diagnosis, and the balance was made up of adults with FASD, birth parents and professionals. The responses as a result focus primarily on the diagnosis and support side of these issues rather than prevention steps. This does not mean that the FASD UK Alliance or stakeholders do not recognise and prioritise the importance of prevention measures. Through our awareness raising we work to ensure the number of cases of FASD drops. We know best the heartache that can avoid.

In our questionnaire we asked people to identify from a list the top five areas where services could be improved for those with FASD or suspected FASD. Respondents identified a significant number of concerns with NHS and other provision for FASD in their areas. These concerns reflect the fact that the respondents were almost all from families where one or more members has already been diagnosed with FASD.

The top five areas identified were:

1. FASD recognised as lifelong disability, with access to services and benefits guaranteed without having to re-test regularly

2. FASD training for medical and other professionals

3. Timely access to diagnosis

4. Someone with FASD should have access to services available to other neurodevelopment disorders such as autism

5. Clear pathway to diagnostic, therapeutic, neurodevelopmental and mental health services

We asked people to indicate how they thought the NHS was doing currently on the areas listed. We then asked people to tell us what they thought was the number one most important thing to address and why. This gave more detail and nuance to the responses. We also asked for a description of the variations they have experienced in service provision.

We promised the people who filled in our questionnaire that we would provide their comments to NICE in full. We believe in this case that is extremely important because when reading what people consider the most important issues and why, it emerges that time and time again people are struggling to find ways to convey the importance of a change of mindset – they want the medical community and others interacting with their families to take FASD seriously. They want appropriate diagnosis, support and resources to help them stabilise and enrich their lives. They want to know that people with FASD will have security and support when they are adults. Too often too many doors are closed, leaving a very vulnerable population ‘bereft’ as one parent wrote. The responses below indicate the importance of moving beyond the ‘shame and blame’ game that too often stops people coming forward for help and which casts shadows over those who do.

We appreciate how much information NICE has to digest on this topic. But we do hope you will at least scan through the comments that follow. There is nothing more powerful than hearing the voices of those most directly affected. While there were about 320 who filled out the questionnaire, and not all filled out all sections, please know this is the tip of a very large iceberg.

# Appendix 4: Review flowchart

Records identified through topic engagement  
n = 154

Records identified through IS scoping search  
n = 22

Records identified through ViP searching  
n = 97

Records excluded  
n = 246

Records screened  
n = 273

Full-text papers excluded  
n = 26

Citation searching or snowballing

n=12

Full-text papers assessed   
n = 39

Current practice examples included in the briefing paper  
n = 13

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   [midwives’ knowledge and practice.](https://www.researchgate.net/publication/273039441_Antenatal_Alcohol_Exposure_-_How_Do_Midwives_Advise_Pregnant_Women_An_East_Anglia_Study_of_Midwives'_Knowledge_and_Practice) [↑](#footnote-ref-8)
9. NOFAS-UK (2017) [GP Survey](http://www.nofas-uk.org/?cat=23) [↑](#footnote-ref-9)
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