North East and Cumbria LMS Boards Regional Alcohol Use in Pregnancy Audit

Executive Summary

Alcohol is one of the seven priorities identified by the Local Maternity System (LMS) boards for improving maternal and infant health at a population level. This mapping document was used to develop a greater understanding of the current position of clinical practice in relation to alcohol use during pregnancy. The findings from the mapping exercise were used to inform a series of recommendations for enhancing maternal outcomes in the future.

Alcohol exposure in pregnancy is a common but modifiable risk factor for poor pregnancy and child outcomes (1). FASD and the other documented harms from alcohol in pregnancy are 100% preventable (2). Therefore, given the complexity of the issue, a systemic approach is required to reduce alcohol consumption in pregnancy (3).

Recommendations

1. Training (FTs and networks / LMSs)

- Maternity staff training needs to be standardised across the region and should include all maternity staff. Consistent information and practices should be shared and regularly updated with latest evidence and guidelines.
- Training should be accessed annually and should include the health professional's personal relationship with alcohol. It is important to train maternity staff to cope with women who have consumed alcohol in pregnancy and need support and reassurance when feeling guilty (in accordance with NICE guidelines https://www.nice.org.uk/guidance/CG110/chapter/1-Guidance#pregnant-women-who-misuse-substances-alcohol-andor-drugs).
- Protected time for maternity staff training delivered by PH colleagues would ensure the provision of Alcohol and FASD related training, plus other key PH priorities when time constraints and resources are so demanding.
- Every Trust should provide their midwives with access to a copy of 'Understanding Fetal Alcohol Spectrum Disorder: A Guide to FASD for Parents, Carers and Professionals' by Maria Catterick and Liam Curran.
- FASD training and the effects of alcohol in pregnancy should be incorporated into the core training of specialist alcohol and substance misuse providers across the region.

2. Maternity Service Provision (Clinicians, FTs, networks / LMSs and commissioners)

- To establish an expert health professional working group specialising in alcohol in pregnancy. This is will raise the profile of the risks of alcohol in pregnancy and facilitate the sharing of best practices across the region.
- To develop alcohol screening practices, services and patient pathways need to be developed and standardised across the region to facilitate referrals and support regardless of location.

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- Every Trust in the region should have an alcohol or generic substance misuse guideline.
- An antenatal specific screening tool should be considered to maximise the detection of women consuming alcohol in pregnancy.
- **Any** maternal disclosure of alcohol consumption in pregnancy **must** be recorded in the antenatal notes. This is because documented evidence of any maternal alcohol consumption in pregnancy or Prenatal Alcohol Exposure (PAE) in the mother's medical records has historically been a requirement of FASD diagnosis for those children who present without the classic Fetal Alcohol Syndrome (FAS) facial dysmorphia. It is important to note that the amount, frequency and timing of alcohol consumption are useful to record but not crucial for the purposes of FASD diagnosis.
- To include partners whenever possible to engage their support.
- To share resources including maternity booklets and websites, the Baby buddy App, the Pregnancy book, NHS Choices leaflets, Balance adapted resources, Royal College of Obstetrics and Gynaecology materials, Drink Aware, the free NHS Scotland FASD eLearning resource and the Bounty app**.**
- A combined role of smoking cessation/alcohol/ public health advisor in maternity clinics may be a cost effective resource.
- Specialist support for pregnant women should be commissioned for local alcohol and substance misuse providers. Providers should work together as part of a Local Maternity System to ensure that the services provided meet women's needs and safeguard women and their babies. Specialist care should be accessible when required, and all providers should operate under shared clinical protocols and governance in accordance with relevant initiatives such as Better Births, 2016.

3. **Date Collection and Audit (National system leaders, FTs, networks / LMSs and commissioners)**
   - Consistent and clear data should be collected and documented in designated maternal and neonatal medical notes to facilitate audit and monitoring.
   - An annual audit of local maternity notes to ensure compliance and measure data across the region.
   - 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.
   - Salient electronic alcohol data to be published in National Maternal and Perinatal Institute (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, relevant PH objectives and identify training needs in maternity and paediatric staff.
   - Alcohol in pregnancy data should be incorporated into NHS quality targets such as the CQC to ensure that the issue is regarded as a priority.

4. **Multi agency working** (**clinicians, national system leaders, FTs, networks / LMSs and commissioners)**

- Multi agency collaboration and communication is required to provide a seamless service that meets the needs of pregnant women and their families.
- The use of the red baby book would be a logical resource to share information regarding PAE with paediatrics, the Health Visitor, General Practitioner and even school teachers. A special history page for pre-natal drug and alcohol use should be added to the red book and completed by maternity staff from antenatal records before discharge to the HV and GP. A regional decision to include this information in the red book with immediate effect could be agreed as an interim measure until the red books are updated.
- Any PAE should also be documented in BadgerNet UK, a Regional Perinatal Data Management system and all baby notes, electronic records to share with the multidisciplinary team.
- Training is required for all professionals working with children 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.

5. **General Service Provision** (C**linicians, national system leaders, FTs, networks / LMSs and commissioners)**
    - To add alcohol screening to regular health checks in pregnancy and across primary care.
    - The risks of alcohol in pregnancy should be discussed in
        - ❖ Preconception clinics
        - ❖ Gynae appointments
        - ❖ Sexual health clinics

6. **Public Health Awareness Campaigns** (**Clinicians, national system leaders, networks / LMSs and commissioners)**
    - FASD awareness initiatives such as pharmacy campaigns and collaboration with pubs and off sales outlets could be adopted across the region and regularly reviewed.
    - FASD awareness and the risks of alcohol in pregnancy should be addressed in schools and preferably delivered by trained health professionals.
    - General alcohol agenda needs to be addressed on a society wide scale. This would include Minimum Unit Price initiatives, alcohol availability in the community, education around the risks of alcohol, regulation of the alcohol industry, including advertising and high profile labelling to inform the public of potential risks to health and the unborn. Celebrity endorsement would strengthen the message.

7. **Research and Development (Clinicians, national system leaders, FTs, networks / LMSs and commissioners)**
    - The results of the baseline assessment work with Sheffield University should be shared with all stakeholders across the region to promote an informed plan of service provision. However, the imperfect baseline assessment will predominantly rely on self-report which we know significantly underreports the problem for many reasons including the

stigma of alcohol consumption in pregnancy and the midwife-woman relationship.

- More research is required regarding alcohol screening, the harms of alcohol in pregnancy, prevalence rates, education, staff training, Alcohol-Related Neurodevelopmental Disorder (ARND) diagnosis, FASD prevalence rates, interventions and support. Research should also focus around birth mothers, and the families of affected children.

Purpose and Background

Alcohol is both teratogenic and fetotoxic and passes freely across the placenta to the unborn baby (4). Prenatal alcohol exposure (PAE) is associated with miscarriage, premature birth, stillbirth and low birth weight (4). Alcohol exposure in pregnancy can also cause a range of physical and neurodevelopmental problems in child which fall under the umbrella term Fetal Alcohol Spectrum Disorder (FASD)(5). Significantly, FASD is the most common cause of non-genetic learning disability in the UK (2). The NHS spends £30million pounds per year to screen and diagnose for Down's syndrome which affects approximately 1 in 800 pregnancies and yet there is currently no allocated budget for alcohol screening in pregnancy (6). The UK has an estimated FASD prevalence rate of 1-5% of UK children (7). This equates to at least one child in every classroom with lifelong brain damage and physical, behavioural and / or cognitive disabilities. There is a stark lack of support for these children and their families, who endure the impact of their impairments without the educational, emotional and social support they require to fulfil their potential (5). They frequently remain without a diagnosis, or are misdiagnosed (8). Secondary comorbidities are common and include social and mental health problems such as substance abuse, sexual inappropriateness, educational difficulties, and crime and incarceration (4). The human cost to affected children and their families is enormous. In the UK, there is no data available to calculate the economic impact and burden on the UK health, education, social care services and the criminal justice systems; but the cost of Fetal Alcohol Spectrum Disorders totalled approximately $1.8 billion in Canada in 2013 (9). Public Health England (PHE) estimates every £1 invested in effective alcohol treatment brings a social return of £3. This calculation does not include the economic burden of FASD (10).

Binge drinking, defined as exceeding six units in one day is most common in younger women of childbearing age, and some women now drink as much as men (11). It is estimated that 41.3% of women in the UK consume alcohol during pregnancy; the fourth highest country in the world (7). Half of all pregnancies are unplanned and many women inadvertently consume alcohol before confirmation of their pregnancy (8). Perhaps more importantly, women have received mixed messages around the risks of drinking in pregnancy for decades. The USA public health message was revised in 1981 and recommended that as the safe level of PAE was unknown it was better to

avoid alcohol in pregnancy completely (2). In 2016, the Chief Medical Officer for England updated alcohol recommendations accordingly and advised that the safest approach for women who are pregnant, or trying to conceive, is not to drink alcohol at all (11).

Formulation and Process

The survey was developed with the NE regional alcohol office, Newcastle University, Public Health, Fetal medicine consultants and a local research midwife with a special interest in FASD. Meetings were held with colleagues across the North East and North Cumbria over a two month period.

- County Durham and Darlington NHS Foundation Trust (CDDFT)
- Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH)
- South Tees Hospitals NHS Foundation Trust (STHT)
- North Tees and Hartlepool Hospitals NHS Foundation Trust (NTHH)
- Gateshead Health NHS Foundation Trust (GHFT)
- South Tyneside NHS Foundation Trust (STFT)
- Northumbria Healthcare NHS Foundation Trust (NHCT)
- City Hospitals Sunderland NHS Foundation Trust (CHST)
- North Cumbria University Hospitals NHS Trust (NCUH)

Meetings with regional Heads of Midwifery (HOM), members of the local authority commissioned 0-19 team, Trust alcohol liaison nurse/midwife, Public Health representative for alcohol and substance misuse. We had focused discussions around key maternity elements.

Emerging Themes

Networks, Leadership and Coordination

We found that local multi agency partnership meetings addressing alcohol in pregnancy were the exception rather than the norm but Durham PH and STHT in particular have some excellent collaborative working practices. Durham PH has a specific FASD action plan and works with clinicians, Public Health England (PHE), drug and alcohol representatives, Balance, the alcohol office for the North East, safeguarding, police and crime representatives and relevant external providers. Areas such as STFT have a generic alcohol reduction strategy group attended by HOM, PH and council representatives. STHT has a quarterly Maternal, Infant Child Health Partnership meeting which focuses on 6 high impact areas for health visiting and preconception to 5 years. This includes a drug and alcohol subgroup. Attendees

include Clinical Commissioning Groups (CCGs), Local authority, education and maternity services. Initiatives such as Hospital Inpatient Liaison Team (HILT) and the maternity drug and alcohol clinic have resulted from this. NUTH have the Newcastle Treatment group which is attended by providers and commissioners with the objective to address generic alcohol issues. They also collaborate with PROPS - Positive Response to Overcoming Problems of Substance misuse and Changing Lives which provides specialist support for thousands of vulnerable people and their families. NCUH are collaborating with Dr Raja Mukherjee, a leading expert in the UK who diagnoses Alcohol-Related Neurodevelopmental Disorder (ARND) and promotes FASD prevention and education.

The aim to reduce alcohol in pregnancy is underpinned by Health Matters: Giving every child the best start in life. It is also shares objectives with initiatives including Family Nurse Partnership (FNP), the Healthy Child Programme, the drug and alcohol agenda, Change for Life, Making Every Contact Count (MECC), Maternity, Infant and Child health programme, Darlington's Children's plan and Newcastle's Troubled families.

Most localities had a substance misuse specialist role midwife equivalent and obstetrician who covers alcohol within their remit, but none were exclusively alcohol focused. CDDFT previously had an alcohol liaison nurse until two years ago when the service was withdrawn. However, they do still have a judicial midwife attached to Low Newton Prison who addresses alcohol within her service. NHCT has a Trust Alcohol Liaison Service which includes pregnant women. Newcastle PH commissions a women's worker in Changing Lives and there is a Girls are Proud (GAP) group for sex workers. School nurses or the new Public Health and Wellbeing Nurses could provide an invaluable link between health visitors and teachers for the children who have suffered harm from PAE. The diversity of services across the region illustrates the complexity of alcohol related issues and how they impact upon many aspects of our society.

Evidence Based Planning and Commissioning

Durham PH is currently undertaking some baseline assessment work in collaboration with Institute of Alcohol Studies at Sheffield University. The challenges of measuring for alcohol exposed pregnancies have been a challenge cited by many localities. This is because alcohol consumption is known to be underreported across all demographics and creates falsely low prevalence data. Social stigma associated with drinking alcohol, poor recall and difficulty in estimating the alcohol content of some drinks or the volume consumed is thought to result in significant under-reporting (12). The use of Biomarkers is still a novel approach being developed but none yet have the sensitivity and specificity to detect low to moderate levels of alcohol consumption over a long period of time since the last exposure (13).

Only generic substance misuse support services are available to women in every locality, highlighting a gap in provision. None were specifically for pregnant women, but Durham uses a life course approach involving the whole family utilising a 'strengthening families' model.

Metrics and Data Collection

Alcohol screening tools varied from midwife's discretion, AUDIT, AUDIT C and standard antenatal screening questions. NCUT uses a bespoke screen tool amalgamating the best from a variety of tools to meet the needs of a pregnant population with reported good effect.

The thresholds for referral varied from any alcohol in pregnancy being regarded as a concern, to impact on lifestyle and in extreme cases, alcohol related A&E admissions or police referrals.

The alcohol in pregnancy data collected also varied. Many localities asked about preconception alcohol consumption habits. CHST asked about partner's intake. Previous referrals or admissions for alcohol are collected at NHCT. Midwives tended to ask about the timing, amount and frequency of alcohol consumption and the gestation when the woman stopped drinking alcohol but most local Trust antenatal booking documents do not accommodate these details.

All localities asked about alcohol at booking but in many areas only high risk women were asked at later maternity contacts. Some localities identified the need to ask at every contact which is adopted at sites such as STHT.

Documentation was a combination of paper and electronic (dataset/E3/Euroking). The electronic data feeds into National Maternal and Perinatal Institute (NMPI) where alcohol data is collected but was not included in the last report (2015-16).

CHST audit alcohol use in pregnancy through caseload management and referrals to substance misuse clinic. NHCT monitor alcohol units in the booking form which is part of the national Maternity Services Data Set (MSDS) and is submitted to NHS Digital. This data also feeds into the maternity dashboard and Trust performance report. CDDFT audits antenatal records on a three monthly basis. Generally, antenatal alcohol documentation is rarely audited so it is difficult to accurately assess current practices.

Mother's alcohol history tended mainly to be documented in the baby notes in high risk cases but this tends not to be routinely audited across the region. NUTH midwives document mother's alcohol consumption on front sheet of baby record, but generally the red baby book which follows the child until adulthood lacks an alcohol specific question and PAE is not routinely documented.

Most Trusts were unaware of alcohol in pregnancy related advice given in Preconception clinics, Gynaecology appointments & Sexual health clinics but it was

agreed that some high risk drinking behaviours are thought to receive general alcohol advice. Across the region, alcohol is generally discussed with epileptic and diabetic women if they attend preconception clinics. STHT has novel FASD awareness campaigns within the community including local pharmacies, pubs, clubs and alcohol off sales retailers.

Pathways

Patient pathways vary considerably depending on the services available but all endeavour to provide individualised care to pregnant women with the resources available.

Most trusts had a high risk/ substance misuse clinic/ vulnerable women clinics to support women who drink. However, at CDDFT community midwives manage women with alcohol and substance misuses issues within their routine caseload and are trained in Brief Interventions (BI). CDDFT midwives cannot refer to specialist service providers and have to recommend women to self-refer. The Darlington service providers do not share any information regarding engagement and progress with midwives stating data protection as the justification. Therefore, midwives have to support the women with alcohol issues solely reliant on the woman's feedback, which raises concerns.

There are benefits of merged drug and alcohol services as there is a degree of crossover in terms of treatment as well as use. A combined service may be more efficient and highlights the fact that alcohol is a drug of dependence as much as an illicit substance. However, there are also disadvantages of co-location of drug and alcohol services which can view alcohol as a lower priority and may deter 'alcohol-only' users attending shared waiting rooms (14).

Brief interventions tended to be more established for the smoking women but STHT, CDDT, CUHT and NHCT use a stepped approach including BI. Areas such as STFT are currently implementing BI for their midwives.

Extra resources offered to women ranged from general maternity booklets and websites, the Baby buddy App, the Pregnancy book, NHS Choices leaflets, Balance adapted resources, Royal College of Obstetrics and Gynaecology materials, Drink Aware and the Bounty app. NUTH also use Change, Grow, Live (CGL) resources which takes a holistic approach with an emphasis on change. STHT are currently developing a 'My Little One' App offering alcohol and general lifestyle advice including local resources.

Most pathways were locality specific but midwives were aware through training of their local resources. CDDT had the most diverse patient pathways dependant on postcode as they cover 2 councils and 3 CCG providers. Referrals are generally immediate and open access across the region. Darlington providers have immediate access drug and alcohol drop in groups but if women prefer a private one to one appointment there is

a waiting list. Durham providers use a single telephone number across the patch and provide a 16 week appointment to provide general lifestyle advice including the risks of harm from alcohol. STHT has an early bird class for six weeks gestation involving a doll and placenta to cover general PH issues education including alcohol. Later at the booking visit, alcohol is addressed again.

Extra generic alcohol support provision included text services and peer support. Durham providers also operate an alcohol support ambassador scheme. STHT utilises the HILT team model for alcohol intervention to ensure full time cover and access for women in need. Street angels are also available in this area to support young alcohol users on the streets.

Information sharing is an area for development. Resources including the electronic databases, baby notes and red books can be better employed to identify those at risk and alert the appropriate GPs, HVs, and paediatricians, for example. Currently mainly babies deemed high risk have their information shared with the relevant Multidisciplinary team (MDT). The STHT HILT service automatically refers women drinking alcohol to GPs and HVs and their electronic system provides a communication form detailing drugs and alcohol at 16 weeks and 28 weeks gestation.

Workforce and Training

Training is ad hoc with some areas providing annual updates for all their maternity staff. Training is often delivered by substance misuse midwife or in CDDFT, the Public Health lead. NTHH employ the local FASD Network expert, Maria Catterick to deliver their training. FASD day is observed in many Trusts across the region. STHT provide training when new pathways were launched and they have a unique system whereby all maternity staff receive protected time, PH updates on an annual basis. Protected time for training is crucial as clinical demands tend to dominate and may prevent training from taking place. STHT also provide all midwives with a copy of Understanding Fetal Alcohol Spectrum Disorder: A Guide to FASD for Parents, Carers and Professionals by Maria Catterick and Liam Curran. Training is predominantly face to face across the region, but generic alcohol related eLearning resources are also available in Newcastle. NHCT signpost midwives to the NHS Scotland FASD eLearning resource which is free of charge.

Guidelines and resources were taken from CMO, National Institute on Alcohol Abuse and Alcoholism (NIAAA), NOFAS-UK, NHS Choices, Drugs Alcohol Recovery Services (DISC) Drug and Alcohol Recovery Services and FASD Network. NTHH and other Trusts in the northern region maternity network have been advising women not to drink alcohol in pregnancy prior to the updated CMO recommendations of 2016. Substance misuse and alcohol guidelines varied significantly across the North East and North Cumbria and in two Trusts have not yet been written.

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