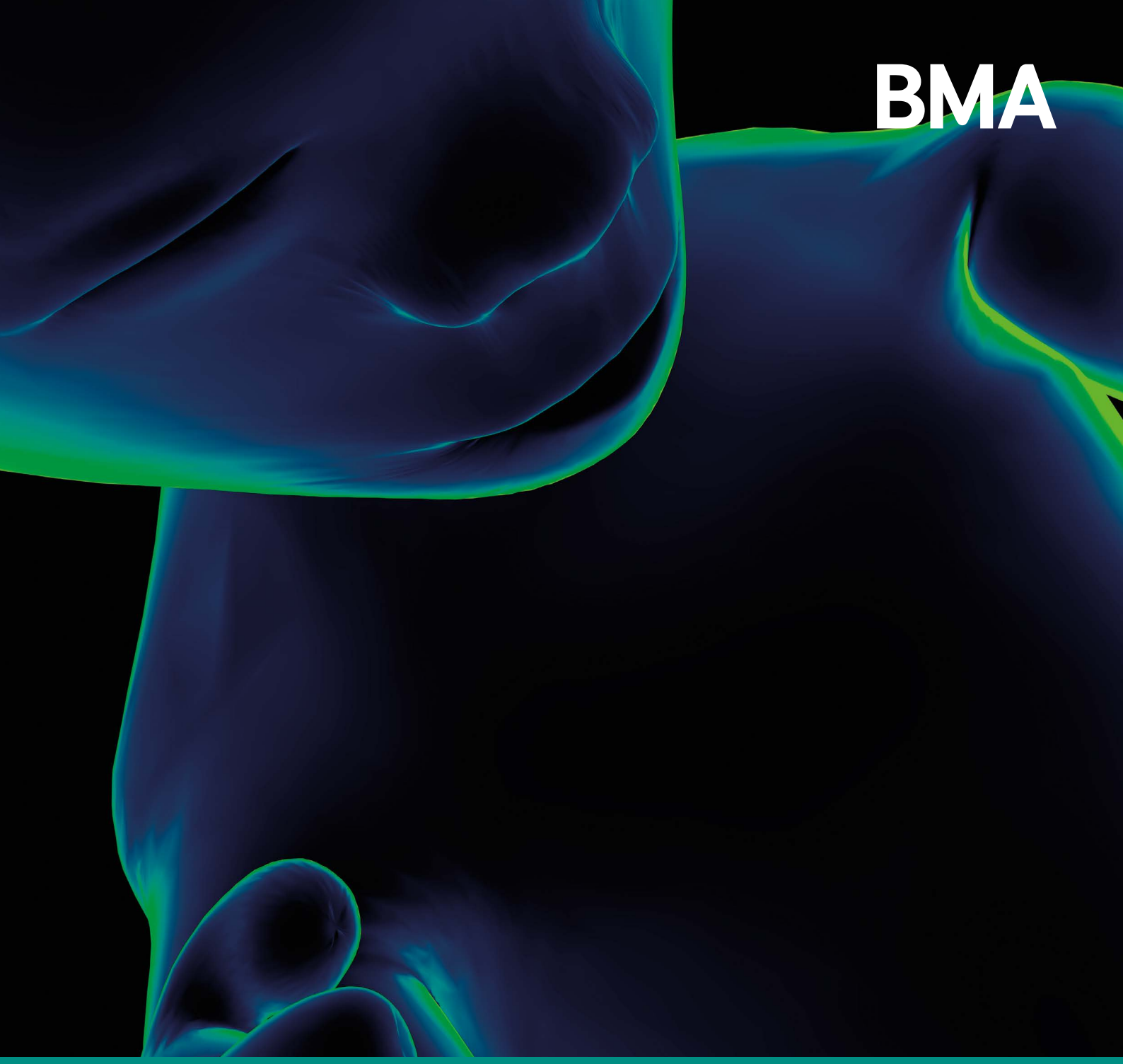

BMA

Alcohol and pregnancy

Preventing and managing fetal alcohol spectrum disorders

June 2007 (updated February 2016)

British Medical Association
bma.org.uk

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Editorial board

A publication from the BMA board of science.

British Library Cataloguing-in-Publication Data.
A catalogue record for this book is available from the British Library.

ISBN: 978-0-9575831-4-6
Cover photograph: iStock by Getty Images

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Approval for publication as a policy report was recommended by BMA council on 12 November 2015.

The board of science, a standing committee of the BMA, provides an interface between the medical profession, the government and the public. The board produces numerous reports containing policies for national action by government and other organisations, with specific recommendations and areas for action affecting the medical and allied professions.

Acknowledgements

The 2007 version of this report was published with the support of a number of outside experts and organisations. We would particularly like to thank:

– Professor Ernest Abel (Professor and Director of Reproductive Toxicology, Department of Obstetrics and Gynecology, C.S. Mott Center, School of Medicine, Wayne State University)

– Professor Peter Hepper (Professor of Psychology and Director, Fetal Behaviour Research Centre School of Psychology, Queen's University Belfast & Royal Jubilee Maternity Service)

– Dr Raja Mukherjee (Consultant Psychiatrist for People with Learning Disabilities, Surrey and Border Partnership Trust)

– Professor Moira Plant (Professor of Alcohol Studies and Co-Director, Alcohol and Health Research Trust, Faculty of Health and Social Care, University of the West of England)

– Professor Edward Riley (Professor of Psychology and Director Center for Behavioural Teratology, San Diego State University).

We are also grateful to Dr Mukherjee for his guidance in producing this updated version.

Declaration of interest
For further information about the editorial secretariat or board members please contact the BMA professional policy division at: info.science@bma.org.uk

Abbreviations

APA	American Psychiatric Association
APPG	All Party Parliamentary Group
ARBD	alcohol related birth defects
ARM	annual representatives meeting
ARND	alcohol related neurodevelopmental disorders
CDC	Centers for Disease Control and Prevention
CNS	central nervous system
DH	Department of Health
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (fifth edition)
EU	European Union
FASD	fetal alcohol spectrum disorders
FAS	fetal alcohol syndrome
FAST	fast alcohol screening test
GLS	General Lifestyle Survey
GP	general practitioner
HSCIC	Health and Social Care Information Centre
IoM	Institute of Medicine
ND-PAE	neurobehavioural disorder associated with prenatal alcohol exposure
NHS	National Health Service
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NICE	National Institute for Health and Care Excellence
NICHD	National Institute of Child Health and Human Development
NPEU	National Perinatal Epidemiology Unit
NO-FAS	National Organisation for Fetal Alcohol Syndrome
ONS	Office for National Statistics
PAE	prenatal alcohol exposure
PFAS	partial fetal alcohol syndrome
PSHE	personal social health and economic education
RCOG	Royal College of Obstetricians and Gynaecologists
SIDS	sudden infant death syndrome
SIGN	Scottish Intercollegiate Guidelines Network
UK	United Kingdom
US	United States

Please note: *that any reference in this report to fetal alcohol spectrum disorders refers to the full range of disorders that can arise as a result of prenatal alcohol exposure.*

Defining alcohol consumption levels

In the UK, alcoholic drinks are measured in units and each unit corresponds to 7.9g (grams) or 10ml (millilitres) of ethanol. The value of one UK unit does not necessarily correspond to a typical serving size. For example, one unit of alcohol approximates to half a pint of ordinary strength beer, lager or cider (3-4% alcohol by volume), or a small pub measure (25 ml) of spirits (40% alcohol by volume). There are one and a half units of alcohol in a small glass (125 ml) of ordinary strength wine (12% alcohol by volume) or a standard pub measure (35 ml) of spirits (40% alcohol by volume). There is also considerable variation in the standard measures used in bars and restaurants as well as measures poured in the home. Different methods are used to define standard measurements internationally that may not necessarily correspond to the UK unit.

In studies that report alcohol consumption levels there is little standardisation in the definitions of heavy, moderate and low drinking. The ONS (Office for National Statistics) defines heavy drinking as eight or more units for men and six or more units for women on at least one day in the week. Moderate drinking is an inexact term for a pattern of drinking that is by implication contrasted with heavy drinking. It denotes drinking that is moderate in amount and does not cause problems. Binge drinking can be considered to refer to heavy drinking during the course of an evening or similar time span (ie heavy episodic drinking).[1] Accordingly, the UK health departments use the ONS definition of heavy drinking as a proxy for binge drinking. It should be noted that in January 2016 the UK chief medical officers published proposed new guidelines on alcohol consumption: that to keep health risks from drinking alcohol to a low level both men and women are advised not to drink regularly more than 14 units per week.[2]

Foreword by Professor Sheila the Baroness Hollins

It has long been known that maternal alcohol consumption can have damaging effects on the fetus. Yet the stark reality is that a large number of children are born every year in the UK with lifelong physical, behavioural and / or cognitive disabilities caused by alcohol consumption during pregnancy.

Worse still, there is a scandalous lack of support for these children, who live and grow up with the impact of their impairments without the educational, emotional and social support they require to fulfil their potential. Too often they go without a diagnosis, or are misdiagnosed. They are also frequently affected by a range of secondary comorbidities, including social and mental health problems such as substance abuse or sexual inappropriateness, educational difficulties, or crime and consequent incarceration.

It is vital that we look at what preventive, medical and social care resources are needed to reduce the number of children born with fetal alcohol spectrum disorders, and to provide support to those who have been affected. This report sets out a range of measures to help achieve this. On the one hand, we need to consider our society's relationship with alcohol – is it surprising that a pregnant woman chooses to drink alcohol when it is such an accepted and normal part of everyday life for the rest of us? Why is abstinence so often seen as an oddity that has to be excused? It is within this wider social context that we must view alcohol consumption during pregnancy. Only with stronger alcohol policies throughout the UK will we start to change this social norm and create an environment that supports anyone choosing to abstain from alcohol use, and in this reports' context because of the potential of conception.

We need the government to provide clear and consistent advice on the risks of drinking during pregnancy, as well as targeted measures to support women and those around them in having an alcohol-free pregnancy. This should be done without apportioning blame or social stigmatisation, but instead focused on a collective responsibility.

As much of my professional career has focused on raising awareness of the hidden health challenges faced by vulnerable groups, I care deeply about the rights of those affected by fetal alcohol spectrum disorders. They must have access to services that deliver the best possible care. While I recognise the efforts of many individual healthcare professionals and support groups in trying to provide this, only through appropriate guidance, commissioning and resourcing will their needs be met in an equitable way.

I am pleased to see the increased focus among policy makers, professional bodies and in Parliament on the need to take action since the BMA first published its report on this subject in 2007. Yet, it is alarming that awareness of the risks of alcohol consumption during pregnancy remains low, and the needs of those affected continue to go unmet. It is therefore vital that we see stronger commitment and leadership from those who can implement change.

I would like to thank those who have helped to produce this updated report and guided its development. My hope is that the next report published on this subject will be a celebration of the successes that have been achieved.

Professor Sheila the Baroness Hollins

Professor Sheila
the Baroness Hollins

Professor Sheila the Baroness Hollins

Professor Sheila the Baroness Hollins is emeritus professor of psychiatry of disability at St George's University of London, and prior to her retirement was chair of the academic division of mental health for 3 years. She holds an honorary chair in the Department of Theology and Religion, University of Durham. She was president of the Royal College of Psychiatrists for 3 years from 2005 to 2008, and was appointed an Independent member of the House of Lords in 2010. She is currently president of the College of Occupational Therapists. After qualifying at St Thomas's Hospital she was a GP in South London before training in psychiatry. Until she retired from clinical practice in 2006, she had been a consultant psychiatrist in learning disability in South West London for 25 years. She has had two secondments to the Department of Health as senior policy advisor in learning disability and autism. Her clinical and research expertise is in the mental and physical health of people with intellectual and developmental disabilities. She is the chair of Books Beyond Words, a community interest company, which promotes the use of pictures to communicate about health and wellbeing to people with learning and communication disabilities. She was the BMA president from 2012-13, and was appointed as BMA board of science chair in June 2013.

Foreword by Professor Sir Al Aynsley-Green Kt

If you could prevent brain damage in a child would you? The majority of expecting mothers and their partners want the very best outcomes for their unborn infants, and so it may seem unnecessary to ask this question. However, exposure to alcohol before birth is the most important preventable cause of brain damage in children today affecting substantial numbers of children. Its effects range from devastating physical and learning disabilities to subtle damage leading to poor behaviour, violence and predisposition to criminality. The human cost to affected infants and their families is huge let alone the economic impact and burden on our health, education and social care services and on the family and criminal justice systems.

There is concern over the lack of political focus on this major problem in the UK that reflects our acceptance of the dominant profile of alcohol in society. This is in stark contrast to the enormity of the investment in addressing fetal alcohol spectrum disorders as I have seen for myself in countries such as Canada. The time has come for our politicians locally and nationally to grasp the seriousness of the problem and initiate coherent strategies to address it so that expecting mothers and their partners are given reliable information and support in making decisions that affect their infants.

I welcome this outstanding report by the BMA that summarises the international evidence on the effects and consequences of alcohol on the baby before birth. It deserves to be taken seriously.

Government must work with the medical royal colleges and other professional groups to raise public and professional awareness of the problem, fund new research and encourage the commissioning of clinical networks to support affected mothers, families and children. The effects of alcohol during pregnancy should be everybody's business.

Professor Sir Al Aynsley-Green Kt

Professor Sir Al Aynsley-Green Kt

Professor Sir Al Aynsley-Green Kt

Professor Sir Al Aynsley-Green trained at Guy's Hospital Medical School, University of London, then as a children's physician in Oxford and as a paediatric endocrinologist in the Children's Hospital, University of Zurich, Switzerland. He was Clinical and then University Lecturer in Paediatrics and Fellow of Green College, University of Oxford.

He became James Spence Professor of Child Health and then Head of the School of Clinical Medical Sciences in the University of Newcastle upon Tyne, followed by Nuffield Professor of Child Health and Director of Clinical Research at Great Ormond Street Hospital for Children and the Institute of Child Health, University College London. He was appointed the first National Clinical Director for Children in the Department of Health in Government in 2000, before becoming the first independent statutory Children's Commissioner for England from 2005-10, and was knighted by HM the Queen for his services to children and young people in 2006.

He is now Professor Emeritus of Child Health at University College London, and Founder of Aynsley-Green Consulting, engaging with governments and organisations worldwide on children, childhood and children's services.

He is currently the president of the British Medical Association.

Contents

Preface

The board of science first published this report in 2007. The original report had the aim of raising awareness of the range of FASD (fetal alcohol spectrum disorders) that can arise as a result of PAE (prenatal alcohol exposure), and examined the incidence, cause and outcomes of the full range of disorders encompassed by this umbrella term. This updated report retains a strong focus on FASD, outlining the responsibilities of healthcare professionals and the wider medical community in managing and reducing the incidence of these disorders. It also has a wider focus on alcohol consumption during pregnancy, including consideration of the broader social context of the nation's relationship with alcohol.

Recently there has been renewed political focus on alcohol and pregnancy, including the establishment of an APPG (all party parliamentary group) for FASD. The group chaired by the MP Bill Esterson and supported by the charity FASD Trust, have recently completed an Inquiry into the picture of FASD in the UK. In January 2015 Bill Esterson MP introduced – to the Commons – a Private Member's Bill on alcohol labelling, which called for mandatory labelling of alcoholic drinks, with respect to the risks of drinking whilst pregnant.[a] Highlighting the continued need for action in this area, the BMA 2015 ARM (annual representative meeting) unanimously passed a resolution calling for UK governments to focus leadership and resources on addressing the consequence of alcohol use in pregnancy.

Since the first publication of this report, overall alcohol consumption among women has declined, yet, instances of heavy drinking remain persistently high. This updated report highlights the importance of continued action to address the ongoing lack of awareness about the potential consequences of alcohol consumption during pregnancy; the absence of national guidance for the diagnosis or referral of FASD; and the lack of adequately resourced services for the diagnosis and management of FASD in the UK. It also reaffirms the need to provide clear and consistent information to all women with respect to the risks of alcohol in pregnancy.

A range of key recommendations are set out for government, policymakers and professionals that aim to help prevent PAE and improve the lives of those affected. These include the implementation of stronger universal prevention strategies to reduce population level alcohol consumption; targeted prevention strategies for those at high-risk of prenatal alcohol exposure; and the development of multidisciplinary teams for the diagnosis and clinical management of FASD.

This updated version is supplemented by a new appendix (**Appendix 1**) that considers some of the ethical and moral issues associated with alcohol consumption during pregnancy.

a The 2014-2015 session of Parliament has ended and this Bill will make no further progress.

Chapter 1
Introduction

1

Chapter 1 – Introduction

Alcohol is a teratogenic compound (ie a substance that interferes with the normal development of the embryo or fetus) that readily crosses the placenta, potentially causing cell death and / or inhibiting cell growth.[3] In the absence of a developed blood filtration system, the fetus is totally unprotected from alcohol circulating in the blood system. There are a number of ways PAE can affect the fetus, and these can result in a wide range of problems. The most severe effects are the intellectual disabilities associated with the adverse impact of alcohol on fetal brain development and the CNS (central nervous system). Damage to the brain is often, though not always, accompanied by distinctive facial deformities, physical and emotional developmental problems, memory and attention deficits, and a variety of cognitive and behavioural problems. Affected individuals are also at a high risk of developing a range of secondary comorbidities including mental illness, alcohol and drug addiction.

Over the past 40 years, considerable attention has focused on the role of PAE in the occurrence of a wide range of disorders classified under the umbrella term FASD. This is a non-diagnostic term that covers several medical diagnoses, from the full presentation of FAS (fetal alcohol syndrome), to a set of conditions – including PFAS (partial fetal alcohol syndrome),[b] ARBD (alcohol-related birth defects) and ARND (alcohol-related neurodevelopmental disorders) – that show some, but not all, of the features of FAS.[3] The APA's (American Psychiatric Association) 2013 publication DSM-5 (Diagnostic and statistical manual of mental disorders, fifth edition) includes criteria defining ND-PAE (neurobehavioural disorder associated with PAE) (see **Appendix 2**).[4] This term is increasingly being used and is intended to encompass the full range of developmental disabilities associated with prenatal exposure to alcohol.

International data indicate that these conditions are associated with a significant financial burden. The adjusted lifetime cost of care for each individual with FAS in the US has been estimated at US $2 million,[5] and the overall annual cost of FAS estimated at approximately US $3.6 billion.[6] In Canada it has been estimated that the annual costs attributable to FASD in 2013 were between C$1.3 and C$2.3 billion.[7] The highest contributor to these annual costs was the estimated loss of productivity as a result of disability and premature mortality.[7] Based on data from the US, it is estimated that the annual cost of FASD in the UK is over £2 billion.[5,6]

Although a significant amount of research has focused on PAE and FASD, particularly in Canada and the US, there has been limited work on this in the UK. Determining the incidence of FASD is complicated by a lack of reliable and consistent data collection, and the difficulty in diagnosing the range of disorders. The incidence of FASD, either in the UK or internationally, is not therefore accurately known. The relationship between maternal alcohol consumption and the development of the range of disorders is also not fully understood. The level and pattern of alcohol consumption, and the stage of pregnancy during which alcohol is consumed are important determinants of the outcome of an alcohol-affected pregnancy,[8,9] as well as genetic vulnerabilities and environmental factors.[10]

FASD are completely preventable through the elimination of drinking during pregnancy. Approximately 50 per cent of adult women in the UK drink weekly, with half of those drinking more than three units of alcohol on at least one occasion a week.[11,12] Prevention requires a good understanding of the continuum of permanent birth defects associated with FASD, and an increased awareness of the risks of PAE among the general public and in particular women who are pregnant or considering a pregnancy. There is, however, a poor understanding of FASD in the UK by the general public and healthcare professionals.[13,14] Further preventative measures include screening of pregnant women for maternal alcohol consumption, referral for brief interventions, and targeting of women at high risk of an alcohol-affected pregnancy. The effective management of FASD necessitates cooperation between a wide range of healthcare professionals as well as individuals in

b PFAS is also termed PFAE (Possible Fetal Alcohol Effects).

the fields of education and social services.[3] Following diagnosis it is vital that appropriate treatment and support systems are implemented at the earliest possible stage to ensure the best outcomes for the child and their family, as well as to prevent the onset of secondary problems.

Chapter 2
Fetal alcohol spectrum disorders

2 Chapter 2 – Fetal alcohol spectrum disorders

The adverse effects of PAE on the developing fetus and child lie within a continuum and represent a spectrum of structural anomalies, and behavioural and neurocognitive impairments. The range of phenotypes associated with FASD vary in severity and clinical outcome depending on the level, pattern, and timing of maternal alcohol consumption. Individuals defined as having FAS – which is the most clinically recognisable form of FASD – exhibit the full phenotype which is characterised by a pattern of anomalies including:

- CNS dysfunction – damage to the CNS results in the permanent impairment of brain function that may lead to intellectual and developmental disabilities, attention deficits, poor social understanding, hyperactivity, poor coordination and planning, poor muscle tone, verbal working memory deficits, receptive language deficits, executive functioning deficits (eg difficulty in organising and planning), slower processing speed and the inability to learn from the consequences of their behaviour
- facial dysmorphology – FAS is commonly associated with abnormal facial features including short palpebral fissures, a thin upper lip vermillion and a smooth philtrum (see **Appendix 3**)
- pre- and post-natal growth deficiency – babies born with FAS are commonly smaller than other babies and typically remain smaller throughout their lives.[15]

The clinical features of other forms of FASD – including PFAS, ARBD and ARND – are less well defined. With each phenotype, the affected individuals exhibit some, but not all, of the characteristic triad of anomalies associated with FAS. PFAS, ARBD and ARND are not necessarily less severe than FAS, as the individual anomalies associated with these conditions may confer the same level of damage that occurs in FAS.[16] Children affected by PFAS usually display a characteristic pattern of minor facial anomalies, deficits encompassing intellectual disabilities, hyperactivity with attention deficit, impulsivity, short attention span, and are developmentally delayed in comparison to other children.[17] ARND are characterised by the presence of prominent neurocognitive deficits and the absence of growth and facial anomalies. Children with ARBD have pronounced behavioural features or congenital structural abnormalities, and lack most of the facial anomalies characteristic of FAS. Clinical criteria for ND-PAE, proposed by the APA, are designed to encompass all developmental disabilities associated with PAE (see **Appendix 2**). These criteria allow ND-PAE to be diagnosed in the absence or presence of the physical effects – including facial features – of PAE.[4]

The neurocognitive deficits associated with CNS dysfunction mean that individuals affected by FASD may experience additional problems as a result of difficulties in learning, judgement, planning and memory. These include psychiatric problems, disrupted school experience, trouble with the law, confinement, alcohol and drug problems, and inappropriate sexual behaviour.[3] Data from Canada indicate that young people (aged 12-17) diagnosed with FASD are 19 times more likely to be incarcerated within the criminal justice system than those without FASD.[18]

2.1 Epidemiology

There is currently no reliable evidence on the incidence of FASD in the UK. In England and Scotland, data are only collected on FAS and not the whole spectrum of FASD. A significant factor limiting surveillance studies for FASD is that it is rarely a reason for hospital admission, or a primary reason for referral. According to hospital episode statistics from the HSCIC (Health and Social Care Information Centre), in England 252 people were recorded as receiving a diagnosis of FAS in 2012-13.[19] A separate study using hospital episode statistics highlighted limitations in the recording of FAS and FASD, and concluded there was a strong likelihood of underreporting.[20] Other studies have highlighted the lack of consistency in the diagnostic criteria for FASD, which hinders accurate estimates of incidence and prevalence.[21] In 2010, the Scottish Paediatric Surveillance Unit launched an enhanced FAS surveillance survey. This is conducted on a monthly basis and asks paediatricians to record whether they have seen children with the clinical features of FAS or diagnosed children with FAS. Between January 2010 and May 2013, 35 definite cases of FAS were recorded, and 15 possible /

probable cases.[22] In Wales there were seven inpatient admissions associated with FAS recorded between 1999 and 2011, but additional data suggest the number diagnosed in a single year was much higher (53 in 2009).[23] There are currently no data available for the incidence of FAS in Northern Ireland.

The prevalence of FAS and FASD have been investigated in a number of countries, including South Africa, Canada, Australia and Italy (**Figure 1**).[24] It is estimated that worldwide 0.97 per 1,000 live births are affected by FAS.[25] It is important to note, however, that this estimate is based almost entirely on data from the US.[25] The estimated rates of FAS and FASD vary greatly in the research literature, which in part reflects the differences between studies in terms of sample size and methodology. Higher rates of FASD have been estimated among children in foster care, and those in the correctional system.[24] A study published in 2015 – assessing FASD in a population of foster and adopted young people referred to a children's mental health centre in the US – indicated that 29 per cent of individuals met FASD criteria, of which 86 per cent were undiagnosed.[26] FAS, although not a common condition, is nevertheless regarded as the leading known cause of non-genetic intellectual disability in the Western world.[27,28]

Figure 1 – International estimates on the prevalence of FAS and FASD

- Estimates on the prevalence of FAS in the US vary between 0.5 and seven per 1,000 live births.[29] Studies suggest that the prevalence of FASD may be as high as two to five per cent among school-aged children in North America and Western Europe.[29,30,31]
- In Australian aboriginal populations the prevalence of FASD is estimated as 4.7 per 1,000 live births.[32]
- The prevalence of FASD in the Western Cape Province of South Africa has been reported to be as high as 68.0 to 89.2 per 1,000 children.[33]
- A study in Italy estimated a rate of FAS of between four and 12 per 1,000 children, and a rate of FASD of between 23.1 and 62.6 per 1,000 children.[34]

More research is required to better understand the prevalence of FASD in the UK, which should include meta-analysis of existing data as well as population specific prevalence studies. A key complication in determining the incidence of FASD is the absence of robust and routine data collection. This is partly due to the uncertainty and debate regarding the range of conditions associated with PAE, and the difficulty in the diagnosis of the range of FASD (see **Section 6.1**). The lack of accepted diagnostic criteria may explain why data on FASD are not routinely collected in the UK, and, where data are collected, are restricted to FAS. In some countries – including Australia, Canada, New Zealand and the US – FAS is or has been one of the diagnostic categories for which data are collected by the respective national paediatric surveillance units. These data are not recorded by the British Paediatric Surveillance Unit.[c] Studies based on data from passive surveillance systems, such as hospital episode statistics, therefore have major limitations: reliance on the correct diagnosis by medical professionals, and on individuals needing a hospital admission. Record based systems are likely to underreport FASD – for example, many children with FASD are never diagnosed, or even referred for diagnosis – which highlights the need for studies using active case ascertainment[j,34] Alongside active case ascertainment, achieving accurate estimates on incidence and prevalence also requires the development and implementation of uniform criteria for the diagnosis of FASD.[21,35] It is likely that proposed criteria for ND-PAE (see **Appendix 2**) will increasingly be used in the diagnosis of developmental disabilities associated with PAE.[4] Achieving accurate estimates of incidence and prevalence is particularly important in light of the growing recognition that FASD represents a significant public health issue, with substantial economic and social costs.[36,37] Accurate data on FASD are crucial to inform decisions on prevention, service provision, health, education, and justice policy.

c The British Paediatric Surveillance Unit is a joint initiative of the Royal College of Paediatrics and Child Health, Public Health England and the Institute of Child Health that is responsible for undertaking active surveillance of rare conditions in children in the UK and the Republic of Ireland.

Recommendations

– Data on fetal alcohol syndrome should be routinely collected throughout the UK and consideration given to how this should extend to cover the range of fetal alcohol spectrum disorders.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government.

– Further research should be undertaken to establish the epidemiology of the range of fetal alcohol spectrum disorders in the UK. This should be supported by the implementation of uniform diagnostic criteria and improved data collection, and should include a meta-analysis of existing data, as well as coordinated large scale population-specific prevalence studies. As passive surveillance studies may underestimate prevalence of fetal alcohol spectrum disorders, future research should include active case ascertainment studies.

Action relevant to: UK Research Councils / National Institute of Health Research (England) / NHS Research Scotland / National Institute for Social Care and Health Research (Wales) / Department of Health, Social Services and Public Safety (Northern Ireland) / Alcohol Research UK

Neilette's story...

My name is Neilette. I am 20 years old. Because I have FAS people stare at me. It makes me feel angry. I say to them what are you staring at and they just walk away. My mum was 40 when I was born. Mum and Dad found out I had FAS when I was born. They didn't tell me straight away. They told me I had FAS when I was about 9. My Mum also died when I was about nine. When I was younger, I got the 'mickey' taken out of me from all the kids on the street. I got used to it. Kids bullied me in school and I had a fight and broke my ankle. Then I went to a special boarding school in Gloucester when I was 11 until I was 14. It was terrible. I hated it. I ran away and took the train to London and went to Dad. They took me back to boarding school but I only stayed for a week. Then I moved back to London to a special unit in Beckton for people with special needs. I was there for two years. There was 12 of us. It was alright. I lived with Tasha who was a self-harmer. After two years the term was over and I had to leave and I moved back with my Dad. It's hard for me to handle money and make change, but I do pay half my bills. It's also hard for me to remember things. If my dad asks me to go down to the shops to get four things I come back with three things because it is difficult to remember. It's hard for me to keep friends. The good things in my life are my Dad and the MAP Newspaper. It's a paper for people with learning disabilities. I am the advertising manager. I go in every day. I made some nice friends. The fire brigade man wants to put some advertising in the paper. And that's all down to me. Another good thing is my dog, Sophie. She's an Alsatian Collie. I think my life is difficult because I am not the same as anyone else and that makes my life difficult. The things that are difficult are like having friends and knowing they are not really your friends. I wish people were more understanding. What I think people should know about FAS, they should come to NOFAS [National Organisation for Fetal Alcohol Syndrome] and learn about it.

Case study originally sourced for the 2007 version of this report.

Chapter 3
Alcohol consumption in women of childbearing age and during pregnancy

3

Chapter 3 – Alcohol consumption in women of childbearing age and during pregnancy

The majority of adult women in the UK consume alcohol at least occasionally. Survey data indicate that approximately 75 per cent of women over 16 in Great Britain consume alcohol at some point over the course of a year.[11,38,39] According to data from the ONS 26 per cent of women in Great Britain reported consuming more than three units on any one day in the previous week, and 11 per cent reported consuming more than twice this.[11] Thirty per cent of women aged 16 to 44 consumed more than three units in a day, and 16 per cent more than six.[11]

Data from the 2011 GLS (General Lifestyle Survey) and from HM Revenue and Customs indicate that alcohol consumption across the UK has fallen over the last several years. The average number of units consumed per week for women has similarly been in decline, and has fallen from 9.4 units in 2005 to 7.6 in 2010.[40] In Scotland, the mean weekly alcohol consumption for women fell from 9 units in 2003 to 7.4 units in 2011, with the percentage of women who consumed more than three units in a day falling from 37 to 33 per cent over the same period.[38]

Despite the decline in overall alcohol consumption among women, instances of heavy drinking remain high. The proportion of women who report report consuming more than three units in a single session has been consistently high, approximately one third between 2005 and 2012.[11,40] The trend towards harmful drinking is especially apparent among young women.[41] ONS data indicate that women aged 16 to 24 drink less frequently than older women, but are more likely to engage in 'binge drinking' (ie drinking more than six units of alcohol on a single day).[11] These drinking patterns may increase the risk of offspring being affected by PAE.[14] In 2011, in Great Britain:

- 14 per cent of women aged 25 to 44 drank more than six units on any one day in the previous week, compared to the 1998 figure of 11 per cent
- 34 per cent of 16 to 24 year old women who reported consuming alcohol in the previous week reported consuming more than six units of alcohol on any one day. 28 per cent of those women reported consuming more than nine units
- just two per cent of women aged 16 to 24, and five per cent of those aged 25 to 44 reported drinking on five or more days of the previous week, compared to 13 per cent of women over 45. One study found young women in North West England reported average consumption of 16.5 units of alcohol in one night.[11,42]

Changes in the drinking habits of women have been associated with a rise in alcohol-related morbidity and mortality – alcohol-related deaths among women in the UK increased from 7.9 per 100,000 in 2002 to 8.3 per 100,000 in 2011.[43] Evidence of the burden of alcohol related harm is apparent across the UK.

- In 2012, there were 79,600 hospital admissions in England for women where the primary diagnosis was an alcohol related condition.[19]
- In 2010/11, there were 11,079 hospital admissions in Scotland for women where the primary diagnosis was an alcohol related condition.[44]
- Alcohol related deaths among English and Welsh women aged 35-54 years doubled between 1991 and 2011, from 6.3 per 100,000 to 12.6.
- Among Scottish women aged 35 to 54 there were 47 alcohol related deaths in 1991, and 77 in 2011.[44]
- In England, the number of referrals of women to alcohol treatment programmes increased, from 23,484 in 2008/2009 to 26,347 in 2011/2012.[45]
- In 2012 the majority (31%) of deaths from alcoholic liver disease in men and women were among those aged 50-59 years, and more than one in 10 in their 40s.[46,47] If trends in the age of onset of chronic liver disease continue, it may increasingly affect women of childbearing age who may be at risk of becoming pregnant with a liver that is already less able to process alcohol efficiently.

Children in the UK are more likely to engage in heavy episodic drinking than most European countries. A 2012 survey report found that 15 to 16 year olds in the UK reported alcohol consumption and heavy episodic drinking at levels well above the European average.[48] In England in 2012, 74 per cent of 15 year old girls were found to have consumed alcohol, and 23 per cent had consumed 15 or more units in the week prior to being surveyed. 54 per cent of all 15 year old girls who drank in the prior four weeks had got drunk.[49]

Alcohol consumption, and particularly binge drinking, is associated with sexual risk taking and unintended pregnancy.[50] Despite a long-term decline in pregnancy rates among women aged under 18 in England and Wales,[51] the rate of teenage pregnancies in the UK remains higher than other Western European countries.[52] In England, Wales and Scotland the pregnancy rate in women under 18 was 27.9 per 1,000 in 2012.[51,53] In Northern Ireland, 3.9 per cent of total live births in 2011 were to women under the age of 20.[54] Evidence suggests that unplanned pregnancies are common, not only in young women but in women throughout their child bearing years.[55] Many women, therefore, may continue to consume alcohol, and engage in binge drinking, unaware of their pregnancy.

There are limited and inconsistent data on alcohol consumption during pregnancy. According to ONS data, in 2012 and 2013, approximately one in 10 pregnant women reported drinking some alcohol in the last week.[11,39] The 2010 UK survey on infant feeding indicated that 40 per cent of mothers drank at some time during pregnancy. This represents a 14 per cent decline from the 2005 survey, and continues a downward trend from 1998 when two-thirds of mothers throughout the UK were reported to have consumed alcohol during pregnancy. Of the mothers in this study that gave up or cut down drinking, 86 per cent reported doing so because alcohol might harm their unborn child, and 71 per cent reported receiving information about drinking during pregnancy.[56] In a separate prospective cohort study of pregnant women in the UK – conducted between 2003 and 2006 – the proportion of women drinking during trimesters one, two and three was estimated at 79, 63 and 49 per cent respectively.[57] A further study – using data from women giving birth between 2004 and 2011 – indicated that 69 per cent of women in the UK consumed alcohol in the first trimester, dropping to 34 per cent in the second trimester.[58] European studies involving objective assessments of fetal alcohol exposure indicate that prenatal exposure to alcohol is widespread.[59,60]

Figure 2 – Understanding the key drivers of alcohol consumption during pregnancy

Although maternal alcohol consumption is the direct cause of FASD, there is a need to acknowledge the wider social context in which this consumption takes place. Of particular importance is how alcohol consumption is widespread and normal activity in the UK, with approximately 80 per cent of the adult population drinking alcohol at least occasionally. It is against this backdrop that the harms that are a result of drinking during pregnancy occur. The effective prevention of FASD therefore necessitates strategies that reduce population-level alcohol consumption (see **Section 5.2**).

Beyond the pervasiveness of alcohol in society, there are a range of specific underlying causes that may result in women consuming alcohol during pregnancy. These include:
- drinking before pregnancy is recognised
- a lack of awareness of the risks of alcohol consumption during pregnancy
- alcohol dependence
- social pressures to drink.[61,62]

3.1 Underestimating maternal alcohol consumption

Data on rates of drinking during pregnancy are commonly based on self-reporting and therefore often unreliable as a result of poor estimation, poor recollection and the social stigma associated with heavy drinking during pregnancy. This is compounded by variation in the alcoholic concentration of different types of drink, variation in serving size (ie different sizes of wine glass), and the difference between the standard measures used in bars and restaurants as well as measures poured in the home.[63] Maternal alcohol consumption levels are therefore often significantly underestimated, and comparative studies of HM Revenue and Customs data and survey data indicate that survey estimates of alcohol consumption may only represent 55 to 60 per cent of the true figure.[64] In a prospective cohort study of women aged 18 to 45 in the UK, over 50 per cent of participants reported alcohol intakes of two units per week during the first trimester of pregnancy, with 28 per cent drinking more than two units per week in the third trimester of pregnancy.[57] Inconsistent data on maternal alcohol consumption can lead to difficulties in studying the association between alcohol and poor health outcomes, and in recording patient histories of alcohol consumption. Underestimating alcohol consumption can also affect an individual's perceptions of their level of drinking and how much they think is safe to drink. Data from the British Beer and Pub Association indicate that on-trade[d] consumption has declined markedly over the last twenty years, and off-trade alcohol consumption has increased.[65] This has implications for future self-reported statistics – alcohol consumed in the home setting is unlikely to be measured, and likely to be at a higher level than that consumed on a licensed premise.[66]

3.2 Is there a safe level of exposure to alcohol during pregnancy?

The damage caused by alcohol on the developing fetus is dependent on the level of maternal alcohol consumption, the pattern of alcohol exposure, and the stage of pregnancy during which alcohol is consumed.[67,68,73] This is confounded by a number of other risk factors including the genetic makeup of the pregnant woman and the fetus,[e] the nutritional status of the pregnant woman,[f] hormonal interactions, polydrug use (including tobacco use), general health of the expectant mother, stress, maternal age, maternal gravidity (number of previous pregnancies) and maternal parity (number of births).[3,68,69,70,95]

There is robust and consistent evidence from human and animal studies that heavy maternal alcohol use is associated with FAS, and the dose relationship between heavy maternal alcohol use and the most severe structural and neurocognitive defects is now widely accepted.[8,9,71] This is particularly apparent in cases of alcohol dependence or severe alcohol problems.[9] However, only four to five per cent of children born to women who consumed large amounts of alcohol during pregnancy are affected by the full syndrome presentation.[8] The pattern and duration of drinking are important considerations in defining the risk of heavy drinking during pregnancy. The occurrence of FAS has been found to be associated with the frequency of heavy dose drinking (ie binge drinking).[25,72] Women who binge drink are much more likely to have children with facial dysmorphology, cardiac anomalies or cognitive impairment than women who drink the same total amount of alcohol over an extended period of time.[72] Studies have generally found that populations with the highest rates of frequent binge drinking have the highest incidence of FASD, whereas populations where alcohol is consumed at lower levels, over a longer period of time, will have fewer cases of FASD overall, more cases of PFAS than FAS, and more cases of ARND than FAS.[68]

The stage of pregnancy during which alcohol is consumed determines how and which cells of the developing fetus are affected. Research has shown there to be vulnerable periods of neonatal development that can be adversely affected by exposure to heavy doses of alcohol intake.[3,8,9,67,76] Evidence from animal experiments suggests these critical periods of exposure occur during the first and third trimesters in humans. Studies in mice have found the very

d On-trade refers to alcohol consumption on licensed premises such as pubs, bars and restaurants.
e Research to identify specific genetic factors contributing to FASD has found that polymorphisms of the gene for the alcohol dehydrogenase enzyme ADH1B in the mother and the fetus, can contribute to FASD vulnerability.
f Undernutrition is associated with antioxidant deficiency, which permits the accumulation of free radicals, which in turn increase the likelihood of cell damage.

early stages of embryogenesis to be critical periods for damage to the developing brain and induction of alcohol-induced craniofacial alterations.[73,74,75,76] Prenatal alcohol exposure during the third trimester is highly-related to damage to the cerebellum, hippocampus and prefrontal cortex.[67] A small-scale study examining children with school problems who had been prenatally exposed to alcohol found that damage to the cerebellum can also occur following heavy maternal alcohol consumption during the first trimester of pregnancy.[77] The occurrence of anomalies characteristic of the range of FASD is not fully understood. It has been suggested that they result from exposure to heavy doses of alcohol intake on specific days of fetal development, and that exposure to heavy doses throughout pregnancy results in the development of the pattern of anomalies found in FAS.[72,73,78]

Existing evidence on the adverse irreversible effects of PAE at low-to-moderate levels is inconclusive and there is currently no consensus on the level of risk or whether there is a clear threshold below which alcohol is non-teratogenic. A 2006 review of the evidence on the effects of alcohol on the developing embryo, fetus and child – conducted by the NPEU (National Perinatal Epidemiology Unit) – found there to be no consistent evidence of adverse health effects from low-to-moderate PAE.[8] Other reviews, including systematic reviews and large epidemiological studies, have drawn similar conclusions.[79,80,81,82,83] A recent prospective cohort study in the US found no association between low-moderate prenatal alcohol consumption and a range of perinatal outcomes.[84] It is worth noting that the current evidence is not robust enough to exclude any risk from low-to-moderate levels,[8] and evidence is continuing to emerge as to the possible effects of PAE at these levels. A 2012 House of Commons Science and Technology Committee report on alcohol guidelines found that there was no evidence for a risk free level of alcohol exposure during pregnancy.[85] Evidence from animal experiments suggests that damage to the CNS may occur even at low levels of alcohol exposure.[3,8,86,87] A 2014 prospective cohort study in the UK indicated that women who consumed alcohol in adherence to national guidelines – of no more than two units per week – during the first trimester of pregnancy, were at increased risk of adverse birth outcomes.[57] A separate prospective study of 501 mother-child dyads found that the child's behaviour at age six to seven was adversely related to low-to-moderate levels of PAE.[88] A dose-response relationship between the level of alcohol consumed and the behaviour exhibited was also found.[88] Another large prospective study indicated that occasional low-to-moderate drinking during the first trimester may have a negative and persistent effect on children's mental health.[89] Studies examining the effects of alcohol on the fetus have shown that exposure at low-to-moderate levels can alter fetal behaviour (see **Appendix 4**). These studies have consistently shown that acute exposure to one to two units of alcohol rapidly suppresses fetal behaviour through a rapid decrease in fetal breathing.[90,91,92,93] Studies examining the effects of chronic consumption indicate that low-to-moderate levels of exposure (two to five units per week) elicit a developmental delay in the functioning of the fetus's nervous system and may result in a permanent effect.[94,95] It is not currently clear what effect these changes in behaviour have on fetal development and the health outcomes of pregnancy.

Clarification is required as to the effect of different levels, patterns and timings of PAE on the health outcomes of pregnancy. There is a significant amount of research focused on this area. It is important that this is consolidated with further research to generate a consensus on the relationship between different levels of PAE and the range of conditions associated with FASD. This would then help to provide clarification on whether there is a safe threshold for PAE. Many of the epidemiological methods used to examine the risk factors associated with FASD have been based on retrospective analysis of studies that did not initially set out to specifically assess FASD, and may therefore lack the sensitivity to pick up some of the deficits associated with PAE. It is important that future research – if methodologically possible – is prospective, and based on whole populations with better recording and stratification of alcohol dose levels. This research should include a range of measures in order to differentiate outcomes between groups. It is worth noting that the number of variable factors in any given pregnancy makes the concept of a 'safe threshold' potentially meaningless, as a 'safe level' of consumption in one individual or group, may be dangerous in the next.

Recommendation

– Further research should be undertaken in the UK to examine the relationship between prenatal alcohol exposure and the range of conditions associated with fetal alcohol spectrum disorders. Future epidemiological studies specific to fetal alcohol spectrum disorders should be based on whole populations and include a range of measures in order to differentiate outcomes between different groups.

Action relevant to: UK Research Councils / National Institute of Health Research (England) / NHS Research Scotland / National Institute for Social Care and Health Research (Wales) / Department of Health, Social Services and Public Safety (Northern Ireland / Alcohol Research UK.

3.3 Maternal alcohol consumption – effects on the fetus

Prenatal Alcohol Exposure is likely to exert its effects in two ways. Firstly, alcohol is a teratogenic compound. It readily crosses the placenta and is also detectable in the amniotic fluid following maternal alcohol consumption.[96] Evidence from animal studies has found that the disruption of normal fetal developmental processes is likely to occur via multiple mechanisms (**Figure 3**).[3,8,9,97,98,99,100,101,102]

Figure 3 – potential mechanisms of alcohol teratogenesis

– *Disruption of cellular metabolism* – altered glucose utilization and transport, suppression of protein and DNA synthesis, oxidative stress.
– *Impairment of cell acquisition/dysregulation of developmental timing* – altered cell cycle, impaired neurogenesis and gliogenesis, mistimed events of cell generation, migration, neurite outgrowth, synaptogenesis, and myelination.
– *Altered regulation of gene expression* – reduced retinoic acid signalling, effects on other transcription factors, epigenetic changes including DNA methylation, histone modifications and regulation by ncRNA (non-coding RNA).
– *Disrupted cell-cell interactions* – inhibition of L1 neuronal cell adhesion molecule function.
– *Interference with growth factor signalling or other cell-signalling pathways* – reduced functioning of NMDA (N-methyl-D-aspartate) receptors, delayed development of the serotonin system, inhibition of IGF (insulin-like growth factors) I and II.
– *Cell damage/cell death* – apoptosis, oxidative stress, withdrawal-induced glutamatergic excitotoxicity.
– *Secondary sources of damage* – altered placental function or other intrauterine factors, hypoxia/ischaemia, acetaldehyde formation.

These mechanisms are most likely activated at different stages of fetal development and may contribute to the varying patterns of anomalies associated with the various FASD phenotypes.[98] It is important to note that none of the mechanisms can account for all of the different anomalies individually and there is likely to be significant overlap between the mechanism pathways.[97] The resultant premature cell death and disruption of the normal development and placement of cells significantly impacts on fetal development. While this can cause abnormalities in the physical structure of the fetus and impair fetal growth, the impact on neural development is the most debilitating feature of PAE. Cells in the CNS experience more rapid cell death than other cells in the developing embryo as they have a lower toxicity threshold for alcohol.[9] PAE also causes widespread damage to the CNS by disrupting normal neural developmental process (eg maturation of glial cells).[9] This primarily affects the areas of the brain – including the prefrontal cortex, basal ganglia, corpus callosum, cerebellum, and, to some degree, the hippocampus – that are responsible for motor and cognitive skills, learning, memory, and executive functioning,[9,103,104] all of which may be impaired in FAS. Data indicate that the teratogenic effect of alcohol may depend on the genetic capacity of the mother and fetus to metabolise alcohol.[68,105]

A second mechanism of action may be the persistent changes in fetal behaviour resulting from alcohol exposure. It is recognised that prenatal development is not just under genetic control but that the fetus's sensory environment, and motor behaviour actions and reactions all contribute to the normal developmental process.[106] Maternal alcohol consumption has the potential to cause permanent damage to the fetus through continual disruption of the normal developmental processes (see **Appendix 3**). The effects of continual disruption of these processes are unknown. It is important that further research is undertaken to clarify the exact mechanisms of alcohol teratogenesis and establish how they relate to the pattern of anomalies associated with FASD.

Recommendation

– Further research should be undertaken to clarify the exact mechanisms of alcohol teratogenesis and establish how they relate to the pattern of anomalies associated with fetal alcohol spectrum disorders.

Action relevant to: UK Research Councils / National Institute of Health Research (England) / NHS Research Scotland / National Institute for Social Care and Health Research (Wales) / Department of Health, Social Services and Public Safety (Northern Ireland) / Alcohol Research UK.

3.4 Other effects of alcohol consumption on reproductive health

The effects of alcohol consumption on reproductive health are not limited to FASD. Alcohol has been associated with a wide range of disorders that impact the reproductive process, including:

– Infertility – heavy drinking and chronic alcohol misuse is associated with reduced fertility in women and men,[107,108] as well as higher rates of menstrual disorders.[82,108]
– Miscarriage – alcohol consumption is associated with an increased risk of miscarriage as a result of the development of aneuploidy (an abnormal number of chromosomes) or major structural malformations of the fetus.[82] Low-to-moderate alcohol consumption during early pregnancy has been associated with increased risk of fetal death.[109]
– Pre-term deliveries and stillbirth – high levels of maternal alcohol consumption in early and late pregnancy is associated with pre-term labour,[82] and low-to-moderate levels of consumption are associated with an increased risk of stillbirth.[110] Research conducted by the NICHD (National Institute of Child Health and Human Development) and the NIAAA (National Institute on Alcohol Abuse and Alcoholism) has found that PAE may be associated with an increased risk of SIDS (sudden infant death syndrome).[111]

Susan's story...

The first time I heard about FAS I was sitting in a medical lecture. When the speaker discussed the eight main characteristics of FAS, my 10-year-old daughter had seven of them. When he said children with FAS have a 'smaller than normal head circumference', bells went off. I had been to six bicycle shops and no one had a children's bicycle helmet small enough for my daughter's head. Within weeks I had a confirmed diagnosis at Great Ormond Street Hospital... my adopted daughter had FAS. I knew her birth mother was an alcoholic, but never knew that would affect my child for the rest of her life. Now, nine years later, I can recognise many children like my daughter. She is part of a universal family of children prenatally damaged by alcohol. Because of her mature vocabulary and witty sense of humour people presume my daughter is a very bright 19 year old. Though the parts of her brain that weren't damaged by alcohol are very clever, in reality, she has an IQ of 75 and the maturity of someone half her age. What she can do today, she may not be able to do tomorrow. She gets angry at herself and hits herself. Her legs are black and blue. Others get angry at her when she is not consistent. When I tried to explain this to a teacher, I was told, I know your daughter can do it, she did it before, she's just not trying. Like the majority of people with FAS, my daughter can't tell time, do maths or give change. At age 19 her peers have outgrown her. Her closest friend is 12. She is isolated and depressed and often talks about suicide. I love her dearly and I feel her pain. Children with FAS get punished for their disability. Because they look normal, they are punished for being lazy, stubborn and defiant. The reality is, they

can't remember, they can't understand and they can't explain. Some say living with FAS is like having to find one's way around Liverpool with a map of Glasgow. I know many families whose children got the diagnosis too late. Their children have been excluded from school, have run away, become homeless, been victims of violence and abuse, are in prison or have committed suicide. My daughter is lucky because, by chance, I learned about FAS. Though her life will never be normal, it is always improving. She recently took third place in the Riding for the Disabled, RDA Nationals. When parents, schools, doctors and social services know what they are dealing with we can begin to improve lives for children like my daughter and everyone affected. My daughter's disability could have been prevented. Her life is my greatest lesson.

Susan Fleisher, Founder of NOFAS-UK (National Organisation for Fetal Alcohol Syndrome-UK) and the FASD Medical Advisory Panel, the NOFAS-UK Family Support Network.
www.nofas-uk.org

Case study originally sourced for the 2007 version of this report.

Chapter 4
Awareness of fetal alcohol spectrum disorders in the medical profession

4

Chapter 4 – Awareness of fetal alcohol spectrum disorders in the medical profession

The prevention and management of the continuum of FASD requires a good understanding of these disorders among healthcare professionals, including their relationship with maternal alcohol consumption, what intervention strategies are effective, and how they are diagnosed and managed.

A range of evidence – including from qualitative studies, unpublished data and national, regional and local conferences – indicate that FASD are a set of conditions that are poorly understood by healthcare professionals in the UK.[112,113] For example, a 2011 survey of midwives in East Anglia indicated that accurate knowledge of the diagnostic features of FAS is limited.[114] Similar experiences have been replicated internationally.[115,116,117,118,119,120] In the USA, a survey of paediatricians found that even though they were knowledgeable about FAS, they did not feel adequately trained to integrate the management, diagnosis or prevention methods into everyday practice, and were not active in routine anticipatory guidance with adolescents for prevention of alcohol-affected pregnancies.[116] A subsequent 2010 US study showed that only 78.5 per cent of obstetricians and gynaecologists recommended abstinence during pregnancy, despite long standing advice from the US Surgeon General that women should abstain from alcohol during pregnancy.[121] A lack of knowledge about FASD will limit opportunities for diagnosis, prevention and early intervention. It is therefore important that efforts are made to provide training and guidance, and increase awareness of PAE and FASD among healthcare professionals, as well as those working in the fields of social work, criminal justice and education[122,123] – see **Further information** section for details of available learning resources for healthcare professionals.

Recommendations

– Training programmes for healthcare professionals on the prevention, diagnosis and management of the range of fetal alcohol spectrum disorders should be implemented in the UK. Training on fetal alcohol spectrum disorders should also be provided for those working in the fields of social work, criminal justice and education.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government / Department of Education (England) / Department of Education (Northern Ireland) / Ministry of Justice (England and Wales) / Department of Justice (Northern Ireland) / Health Education England / NHS Education for Scotland

– Training on the prevention, diagnosis and management of fetal alcohol spectrum disorders should be integrated into undergraduate and postgraduate curricula and continued professional development.

Action relevant to: Medical Schools Council / Medical Royal Colleges / General Medical Council / Health Education England / NHS Education for Scotland / NHS Wales / Department of Health, Social Services and Public Safety (Northern Ireland)

Chapter 5
Prevention of fetal alcohol spectrum disorders

5

Chapter 5 – Prevention of fetal alcohol spectrum disorders

The prevention of FASD requires a coordinated and multi-faceted approach that incorporates universal prevention strategies aimed at the general population (eg public awareness and educational campaigns); selective prevention strategies aimed at women of childbearing age, in particular those who are considering a pregnancy (eg screening for maternal alcohol consumption); and specific prevention strategies aimed at women who are at high-risk (eg referral to specialist alcohol services).

A multi-sectoral, holistic approach to FASD prevention and management has developed over the past decade in Canada (**Figure 4**). Building on education to raise awareness of FASD, a holistic approach is taken to prenatal care, encompassing stress reduction, nutrition, and a focus on the roots of addiction and alcohol problems. All of these contribute to improving women's health and reducing the risk of having a child affected by FASD. A significant aspect of the Canadian approach to prevention is that advice on alcohol consumption is provided not only to women of childbearing years, but also to their wider support network, including their partners and close family. This underlines the importance of creating a supportive environment for not drinking throughout pregnancy, and recognises that the prevention of FASD is a collective responsibility.

Figure 4 – Overview of the Canadian approach to FASD prevention

Canadian prevention specialists have identified four mutually reinforcing prevention approaches as effective in delivering FASD prevention.[124]

Level 1: Broad awareness building and health promotion efforts

This first level of prevention aimed at elevating public awareness of FASD, as well as where to get help broadly to all sectors of society, including girls and women of childbearing years.

Level 2: Discussion of alcohol use and related risks with all women of childbearing years and their support networks

The second level of prevention involves discussing with all women of childbearing years, and their support networks, alcohol use and related risks, coping without alcohol, the prenatal supports available, and pregnancy planning. This involves system-wide commitment on the part of all service providers working with women to engage in informed and respectful discussion of alcohol and other substance use.

Level 3: Specialised, holistic support of pregnant women with alcohol and other health/social problems

The third level is delivered through specialised, holistic support of pregnant women with substance use, health and/or social problems. Critical to this is a culturally relevant, non-judgmental approach, with accessible and comprehensive services helping to reduce barriers to care. Evaluations of Level 3 prevention services show women who access these services experience improvement in physical health, nutritional status, housing, connection to substance use treatment, parenting capacity and ability to retain custody of their children.[125,126]

Level 4: Postpartum support for new mothers assisting them to maintain/initiate changes in their health and social networks and to support the development of their children

This level involves supporting new mothers to maintain healthy changes in their alcohol use, and providing postpartum support for those mothers who were not able to make significant changes in their substance use. This stage may also involve early intervention services for their children.

5.1 Guidance on alcohol consumption in pregnancy

Guidance on alcohol consumption during pregnancy has been criticised by the scientific community for being variable and confusing.[127] As previously noted, the majority of people in the UK drink alcohol, at least occasionally, and a significant proportion exceed the recommended limits on alcohol consumption. 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 PAE (see **Further information** section for details of available patient information resources on alcohol consumption and pregnancy).

5.1.1 The evidence base for guidance on alcohol consumption during pregnancy

As discussed in **Section 3.2**, there is clear evidence that heavy maternal drinking can adversely impact the developing fetus. The evidence for the adverse effects of maternal alcohol consumption at low-to-moderate levels is inconsistent and inconclusive, with some studies finding no negative impact or impairment,[79,80,81,82,83] and others suggesting the potential for negative effects.[9,10,16,71,122,128,129] The lack of conclusive evidence on the safety of low levels of PAE has led to the existence of varying guidelines and advice on alcohol consumption during pregnancy having a different emphasis (detailed in **Appendix 5**). Guidance from NICE (the National Institute for Health and Care Excellence) specifically recommends that women do not consume any alcohol during the first three months of pregnancy (because there may be an increased risk of miscarriage), and that if women choose to drink alcohol during pregnancy they should be advised to drink no more than one to two UK units once or twice a week.[130] A similar position has been adopted by the RCOG (Royal College of Obstetricians and Gynaecologists), who also state that the only way to be certain that your baby is not harmed by alcohol is not to drink at all during pregnancy or while breastfeeding. [131] The DHSSPS Northern Ireland (Department of Health, Social Services and Public Safety) state that the best advice is to avoid drinking alcohol during pregnancy, but that consuming one or two units once or twice a week is 'highly unlikely' to cause harm.[132] Proposed new guidance from the UK chief medical officers published in January 2016 recommends that the safest approach is not to drink alcohol at all during pregnancy, and that the more that is drunk the greater the risk of harm.[2]

5.1.2 Delivering a clear message on alcohol consumption during pregnancy

There is a need to consider the most appropriate public health message for alcohol consumption during pregnancy, and ensure this is clear and unequivocal. This reflects a number of considerations. Firstly, as noted in the preceding section, there is variation in the emphasis of guidance and advice on alcohol during pregnancy. Secondly, despite the availability of information,[131] recommended guidelines and limits can be misinterpreted as individuals may not clearly understand what units or 'standard drinks' are.[133] Studies have also indicated that providing women with the information about standard drinks, or units, does not appear to prevent them consuming more than they realise.[133] Finally, media reporting of new research findings has a tendency to increase the confusion about the safety of drinking during pregnancy. This was highlighted by a 2011 NHS Choices analysis of media reports relating to alcohol between July 2007 and July 2011:

> *'Women who are trying to get pregnant or are expecting a baby have every right to feel confused about whether they can drink and, if so, how much. This is an important and emotive issue. However, it seems more prone than most topics to contradictory headlines, such as "Binge drink 'is safe for foetus'" (The Sun, November 14 2007) and "Pregnant women told to keep off alcohol" (The Daily Telegraph, October 26 2007).*
>
> *Similarly, The Daily Mail reported: "Pregnant women who drink one or two units of alcohol a week may actually find their child is better behaved than if they abstained" (October 6 2010), only to warn a few months later that mothers who drink in early pregnancy "are more likely to have unruly children" (March 22 2011)."*[134]

Taking these factors into consideration, the BMA believes that, on balance, the safest approach is for women who are pregnant, or who are considering a pregnancy, to be advised not to consume any alcohol. This is in line with proposed guidance from the UK chief medical officers published in January 2016, recommending that the safest approach is not to drink alcohol at all during pregnancy.[2] As noted at the start of this chapter, this advice should also factor in a woman's wider support network, in particular their partners or close family, who will have an important supportive role in an alcohol-free pregnancy.

Recommendation

– Women who are pregnant, or who are considering a pregnancy, should be advised that the safest option is not to consume any alcohol. Relevant stakeholders should work in partnership to ensure guidance and advice on alcohol and pregnancy is consistent and clear.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government / National Institute for Health and Care Excellence / Scottish Intercollegiate Guidelines Network / / UK Chief Medical Officers / Public Health Agency (Northern Ireland) / Royal College of Obstetricians and Gynaecologists.

5.1.3 Providing advice in healthcare settings

Beyond the public health message, there is a need to consider the way in which this message is delivered in a clinical setting, in particular to those women who report having consumed alcohol during their pregnancy. Healthcare professionals have an important role in ensuring those patients that have consumed alcohol do not feel stigmatised, and to reassure patients that – while there is no definitive evidence – the risks associated with drinking small quantities of alcohol are likely to be small. To support this, healthcare professionals should be aware of the uncertainty around the risks of consuming alcohol at low-to-moderate levels during pregnancy, and be comfortable explaining this uncertainty to patients. Where patients declare heavy alcohol consumption, healthcare professionals should be in a position to deliver targeted interventions or refer patients to specialist alcohol services as appropriate (as discussed in **Section 5.3**).

5.2 Universal prevention strategies

As alcohol consumption during pregnancy does not occur in isolation, it must be viewed in the context of society's relationship with alcohol: in the UK drinking is accepted as a normal part of daily life. As highlighted in the BMA's 2009 report *Under the influence – the damaging effect of alcohol marketing on young people*, the alcohol industry makes significant investment into promoting a pro-alcohol social norm.[135] The introduction of policies aimed at preventing the range of FASD therefore need to be considered within the wider context of the overall strategies to reduce alcohol-related harm across the UK. Of particular importance is the need for policies that reduce the overall level of alcohol consumption at a population level. This reflects the relationship between total consumption across a population and consumption among various groups – the higher the mean consumption in a population, the higher the consumption level among women of childbearing age.

There is significant evidence that the most effective ways to reduce the level of alcohol-related harm across the population involve measures aimed at influencing supply and demand. These include reducing the accessibility, availability and promotion of alcohol.[136] To ensure the effectiveness of population-level measures in reducing alcohol-related harm there is an important role for the provision of information and education, to increase awareness as to the risks of alcohol consumption.[136]

Price is a key determinant of access to alcohol, and there is strong evidence that increases in price are associated with decreases in overall consumption, and a reduction in alcohol-related harm.[136,137,138] Young drinkers and heavy drinkers are particularly responsive to changes in price.[139] Despite this, the affordability of alcohol in the UK is exceptionally high, even with rising taxation levels.[137] This highlights the need to significantly increase excise duty on alcohol above inflation. Action is also needed to eliminate the supply of very cheap

alcohol, which the heaviest drinkers use to maintain their consumption despite rising prices or falling incomes. The most effective way of doing so is through the introduction of a minimum price per unit of alcohol.[137,139] Legislation to introduce a minimum unit price was passed in Scotland in 2012, but has not yet been implemented due to a legal challenge led by the Scotch Whisky Association. Devolved administrations in Wales and Northern Ireland have also signalled support for minimum unit pricing, and the Welsh Government is currently consulting on proposals to introduce a minimum unit price for alcohol.[141] Experiences from other countries, and evidence from modelling studies, suggest that the introduction of a minimum unit price will prevent deep discounting of alcohol and lead to steep reductions in alcohol consumption and harm.[137] Doctors believe a minimum price per unit of alcohol should be set at no less than 50 pence.[137]

The availability of alcohol is also known to be an important determinant of consumption and harm.[136,138,140,141,142] In the UK, the liberalisation of licensing laws has resulted in a substantial increase in the availability of alcohol. This trend needs to be reversed, including through action to reduce licensing hours for on- and off-licensed premises.

Beyond measures to reduce the accessibility and availability of alcohol, stronger regulation is needed to limit the way it is promoted, through a comprehensive ban on all alcohol marketing communications. The alcohol industry invests hundreds of millions of pounds a year marketing its products,[41] with advertising and promotion becoming increasingly sophisticated. From social media and the Internet, to associating alcohol with music festivals and major sporting events, alcohol promotion fosters a pro-alcohol social norm, and limits the effectiveness of public health messages. This directly influences the onset, continuance and amount of alcohol consumption among young people. [41,135,143,144,145]

Strategies for elevating public awareness around the impacts of alcohol on the developing fetus are also important, as awareness of FASD among the general population is low. There are currently no requirements for alcohol products in the UK to include warnings about the risk of drinking during pregnancy, instead companies can voluntarily sign up to the UK Government's 'responsibility deal' on alcohol labelling.[146] There is a need for the mandatory provision of clear, consistent warning labels on alcoholic beverages with respect to the health risks of alcohol consumption during pregnancy. The provision of greater education and information on FASD may also help change attitudes and social norms around drinking. To be effective in changing behaviour, however, increased public awareness of the risks of consumption needs to be supported by regulatory measures – as discussed in the previous paragraph – that limit the affordability, availability and promotion of alcohol. Doctors have expressed concern that too little emphasis has been paid to the use of these population-level measures to reduce alcohol consumption.[136,147] A 2015 review of alcohol policies across the four nations of the UK highlighted that the devolved administrations in Scotland, Wales and Northern Ireland had adopted stronger, evidence-based policies to tackle alcohol consumption across the whole population, and that Scotland had the strongest approach overall.[141] By contrast, the UK Government's alcohol policy has tended to be weak and largely ineffective due to an overreliance on partnership working with the alcohol industry.[141] This includes the use of educational initiatives that often have little or no meaningful information about the risks and health consequences of drinking, and may not on their own be effective in changing behaviour.[136,147]

The role of information provision and education about the risks of alcohol consumption needs to be considered as part of a wider strategy for reducing alcohol related harm. Reviews of the effectiveness of school alcohol education indicate that programmes are most effective when they form part of, and are supported by, a comprehensive approach to harm prevention.[148,149] In addition, there is a need to ensure that teachers providing school education on alcohol – including on the specific risks of drinking whilst pregnant – are provided with adequate support and guidance to ensure it is delivered effectively.[148] In Alberta, Canada, clear guidance is available for teachers on the prevention of FASD, including specific resources for teaching children of different ages.[150] To improve awareness of the risks of alcohol consumption amongst children in the UK, high-quality alcohol education programmes should be provided as part of PSHE (Personal Social Health and Economic Education), which include information of the risks of drinking whilst pregnant.

Recommendations

– Alcohol policy should focus on reducing overall consumption in the population, through a range of regulatory and policy measures including:
  – increasing excise duty on alcohol above inflation
  – implementation of The Alcohol (Minimum Pricing) (Scotland) Act 2012, and support for legislation to introduce minimum unit pricing in all four nations of the UK
  – reductions in licensing hours for on- and off-licensed premises
  – a comprehensive ban on all marketing communications.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Public Health Agency (Northern Ireland) / Public Health England / Public Health Wales / NHS Health Scotland / Scottish Government / Welsh Government.

– Measures to reduce the accessibility, availability and promotion of alcohol should be complemented by steps to increase public awareness of the risks of drinking during pregnancy, supported by mandatory labelling of alcoholic products that highlight the health risks of alcohol consumption during pregnancy.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Public Health Agency (Northern Ireland) / Public Health England / Public Health Wales / NHS Health Scotland / Scottish Government / Welsh Government.

– High quality alcohol education programmes that include information on the risks of drinking whilst pregnant should be provided in schools throughout the UK.

Action relevant to: Department of Education (England) / Scottish Government / Welsh Government / Department of Education (Northern Ireland) / PSHE Association

5.3 Selective and indicated prevention – the role of the healthcare professional

Selective prevention strategies target all women of childbearing age and include health promotion and advice, screening of pregnant women for alcohol use, and the implementation of brief interventions as appropriate. Indicated prevention strategies are targeted at women who are at high-risk of having children affected by FASD, and include treatment of alcohol addiction problems where present. It is important to recognise that there are many potential reasons for drinking during pregnancy, and women in different situations are likely to benefit from different types of support and intervention.[61,62]
In their clinical guidelines on alcohol use and pregnancy the Society of Obstetricians and Gynaecologists of Canada set out a range of possible scenarios for alcohol consumption during pregnancy, and provide guidance for healthcare professionals as to the appropriate support to give in each.[151]

5.3.1 Health promotion and advice

Healthcare professionals have a specific responsibility in providing advice to their patients – prior to conception and during pregnancy – on the risks associated with maternal alcohol consumption and on recommended drinking guidelines. This is in addition to the advice provided to patients on other factors such as smoking and poor nutrition. Guidelines on antenatal care developed by NICE recommend that, women should initially receive advice about lifestyle considerations – including alcohol consumption – at the first contact with a healthcare professional.[130] It is important to note that, where possible, advice on risks of alcohol consumption should not just be aimed at women who are pregnant or considering a pregnancy, but also their wider support network.

Healthcare professionals are well placed to implement indicated prevention strategies that target specific demographic groups known to be at higher risk of FASD (see **Section 5.3.4**), and to target women who are pregnant, or may become pregnant, and who drink

alcohol. To effectively target information to those at high-risk of PAE, it is necessary to have an understanding of the range of underlying reasons why women may consume alcohol during pregnancy (summarised in **Chapter 3**).

Various studies have indicated that the provision of advice on alcohol consumption to pregnant women is inadequate. According to the 2010 UK infant feeding survey, the number of pregnant women reporting receiving information about alcohol consumption during pregnancy decreased from 78 per cent in 2000 to 71 per cent in 2010.[56] Advice was most commonly provided by a midwife (81 per cent), while just 13 per cent received advice from a doctor. A 2015 online survey of new and expectant mothers in the UK indicated that over half weren't given any advice on drinking whilst pregnant.[152] A separate survey of midwives in East Anglia indicated that less than a third routinely provided information on antenatal alcohol use.[114] A 2014 study indicated that the majority of women reported hearing about FASD and risks of drinking from the media and rarely from midwives, GPs or obstetricians.[14]

Healthcare professionals – including GPs, obstetricians and midwives – need the necessary time and resources to effectively convey information and advice on the risks of alcohol consumption to women who are considering a pregnancy, and to be able to provide continued advice and support to expectant mothers at every stage of pregnancy, when clinically appropriate.[g] Healthcare professionals should be supported in this through the provision of up to date, clear and evidence based guidance. In some circumstances it may be useful for verbal guidance to be supplemented with 'take home' printed information that provides clear information about the risks of consuming alcohol during pregnancy.[17]

Recommendation

– Healthcare professionals should be supported with the necessary time, resources and guidance to ensure that they are able to provide advice and support to expectant mothers at every stage of pregnancy on the risks of maternal alcohol consumption, when clinically appropriate.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government

5.3.2 Monitoring and detecting maternal alcohol consumption (screening)

Beyond the provision of advice, effective prevention of the range of FASD requires the accurate identification of pregnant women who are consuming alcohol, and the implementation of evidence-based interventions to reduce the risk of PAE. There are currently no specific guidelines to support routine screening of alcohol consumption in antenatal care; healthcare professionals involved in routine antenatal care should be provided with clear guidance on the monitoring and recording of alcohol use among all pregnant women. Accurate consumption histories must be taken sequentially, not retrospectively. The use of screening questionnaires (see **Appendix 6**) may facilitate the identification of at-risk women, allowing safe drinking advice to be offered.

It should be noted that monitoring and detecting maternal alcohol consumption is complicated by a number of factors including:

– an under-reporting of maternal alcohol consumption levels that can occur because women feel afraid or embarrassed to admit they are drinking during pregnancy
– embarrassment on the part of healthcare staff who view monitoring as intrusive
– the difficulty in ascertaining consumption levels in the early stages of pregnancy[h]

g For further information on the autonomy of pregnant women and the right to choose or reject advice or treatment please refer to Medical Ethics Today: The BMA's Handbook of Ethics and Law, 3rd edition, (1) (2012) pp123-124.

h Some women may have been drinking harmful amounts of alcohol prior to detecting their pregnancy and then will have reduced their alcohol consumption levels once they found out they were pregnant. Therefore, asking questions about their alcohol consumption levels during pregnancy may not provide accurate information regarding consumption levels during the initial stages of pregnancy.

– inaccurately recorded patient histories of alcohol use
– poor use of screening techniques and follow-up procedures
– the lack of a reliable biological marker for maternal alcohol consumption.[15,153,154,155]

Current NICE guidance recommends that pregnant women be encouraged to have their carbon monoxide levels tested to determine their exposure to tobacco smoke.[158] Although there are a wide range of screening tests and approaches available – blood tests, urine toxicology screens, self-report measures, structured interviews, and educated guessing based on clinical experience – there is no definitive test that can similarly identify alcohol use during pregnancy or newborns exposed to alcohol prenatally. Several potentially useful biomarkers (eg fatty acid ethyl esters, gamma-glutamyl transferase, carbohydrate deficient transferrin) are available, or being developed, that can detect varying degrees of alcohol exposure or use, although these biomarkers can only pick up limited information about alcohol consumption.[122,154,156,157,158] There are a number of ethical considerations for the use of these methods including the need for informed consent, the fact that detecting a biomarker for alcohol consumption implies a lack of trust in the information provided by the mother, and the fact that the detection process comes too late to educate and prevent harm. Further research is required to establish the validity, efficacy and ethical considerations for the use of biomarkers, with respect to alcohol consumption during pregnancy.

Standardised questionnaire based screening tools can be an effective screening method,[160] offering a greater sensitivity (ability to detect alcohol problems) and specificity (ability to exclude false cases) than biomedical markers. Two similar routine screening methods have been specifically developed in the USA that are brief and can be used to establish alcohol use in pregnant women; the T-ACE and TWEAK alcohol screening questionnaires (see **Appendix 6**).[160,161] A systematic review of seven different screening instruments concluded that that T-ACE and TWEAK questionnaires have similar sensitivities (69-88% and 71-91% respectively) and specificities (71-89% and 73-83%),[162] and have been found to be efficient screening tools for identifying alcohol consumption during pregnancy.[8,163,164,165,166] This review also indicated that the AUDIT-C questionnaire could be an effective screening tool, and may be useful for identifying alcohol dependency and abuse.[160] There is some evidence that the TWEAK questionnaire may be more effective at identifying women who are not problem drinkers but who consume alcohol at low-to-moderate levels.[8] The T-ACE and TWEAK questionnaires are recommended by the DH (Department of Health) and the SIGN (Scottish Intercollegiate Guidelines Network) as simple screening tools for detecting alcohol misuse among pregnant women.[167,168] It is important that screening questionnaires are used as part of routine antenatal screening, and healthcare professionals involved in the provision of antenatal care should be appropriately trained in their use. A number of other screening questionnaires that assess the quantity and frequency of alcohol consumption have been developed; for example the FAST (Fast Alcohol Screening Test) which is a short questionnaire that screens for hazardous drinking as well as harmful drinking and dependence.[169] These screening questionnaires are not specifically designed for use with pregnant women and further research is required to support the implementation of effective screening methods for maternal alcohol consumption in the UK.

In the UK, pregnant women are routinely screened for a number of specific conditions including haematological conditions (eg anaemia), fetal anomalies (eg Downs syndrome), infections (eg rubella) and clinical conditions (eg gestational diabetes mellitus). However, with the exception of Scotland (see **Figure 5**), no guidance is provided on routine screening to specifically monitor alcohol consumption during pregnancy. Current NICE guidelines on antenatal care only include guidance on the provision of advice, and not on the screening of alcohol use during pregnancy.[130] It is necessary that adequate time be provided to healthcare professionals to allow screening for alcohol use to form part of the routine antenatal screening tests provided to pregnant women as a part of NHS care throughout the UK. This would require appropriate training and resources. While objective screening questionnaires have been developed, and guidelines on alcohol screening have been produced to support brief interventions, the provision of comprehensive guidance on monitoring and screening for prenatal alcohol use for all healthcare professionals throughout the UK is still required.

In addition to identifying at-risk pregnancies, routine antenatal screening for maternal alcohol consumption would assist in the identification of those neonates who are at greatest risk of FASD, and women most at risk of subsequently giving birth to an affected

child. The screening process itself would also serve to raise awareness of the dangers of maternal alcohol consumption, and it has been suggested that this alone may be related to a reduction in drinking during pregnancy.[170]

Recommendations

– Adequate time, resources, training and guidance should be provided to healthcare professionals involved in the provision of antenatal care to:
  – allow screening for maternal alcohol consumption – via objective techniques such as T-ACE, TWEAK and AUDIT-C – to form part of routine antenatal care in the NHS
  – ensure that alcohol use among pregnant women is monitored and recorded appropriately.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government

– Further research should be undertaken to examine the most effective screening methods for assessing maternal alcohol consumption.

Action relevant to: UK Research Councils / National Institute of Health Research (England) / NHS Research Scotland / National Institute for Social Care and Health Research (Wales) / Department of Health, Social Services and Public Safety (Northern Ireland) / Alcohol Research UK

5.3.3 Referral for brief interventions

Brief interventions are intended to provide prophylactic treatment before or soon after the onset and identification of alcohol-related problems. Research has found that brief interventions produce clinically significant effects on drinking behaviour and related problems, and are cost-effective.[8,165,166,167,168,171] Many systematic reviews have been published that demonstrate the effectiveness of brief interventions at reducing risky drinking.[159] There is more limited research on the effectiveness of brief alcohol interventions in pregnant women.[172] In some prenatal settings, they have been shown to be a low-cost and effective method of reducing or stopping alcohol consumption during pregnancy in women who are non-dependent and who consume alcohol at low-to-moderate levels.[8,153,163,168,173] Brief interventions in pregnant women may also produce improved birth and neurobehavioural outcomes in their children, and decrease alcohol consumption during subsequent pregnancies in high-risk women.[8,163,174] The effects of brief interventions have been found to be significantly enhanced by partner participation.[176]

Brief interventions commonly consist of a number of stages including assessment, feedback and goal setting.[8,153] They are delivered using behavioural modification techniques and reinforced with the provision of written material. The type of brief intervention that is appropriate is dependent on the level of maternal alcohol consumption, the stage of pregnancy and the severity of dependence on alcohol. Simple brief interventions involve a specific brief interview provided by a competent practitioner immediately following a screening assessment.[167,176] Extended brief interventions incorporate a series of these structured interviews (between three and 12) delivered by a competent practitioner.[167,176] They can be delivered in a variety of settings, including medical settings – such as primary care and accident and emergency – and in generic non-specialist services. NICE have developed a pathway for the delivery of brief interventions for alcohol-use disorders, to those attending services that have been identified as drinking harmfully or hazardously.[177] Routine antenatal care provides an important opportunity to deliver a brief intervention for reducing alcohol consumption, and healthcare professionals working in this setting should be aware of available guidance on brief interventions and trained in their delivery.[167,176,177]

The DH's 2006 report *Models of care for alcohol misusers* provides guidance on the treatment of adult alcohol misusers, including information on simple and extended brief interventions. This outlines the type of advice that should be offered during a brief intervention, including:

– information about the nature and effects of alcohol and its potential for harm
– personalised feedback on risk and harm
– emphasis on the individual's personal responsibility for change
– attempts to increase the patient's confidence in being able to reduce their alcohol

consumption ('self-efficacy')
- goal-setting (for example, start dates and daily or weekly targets for drinking)
- written self-help material for the individual to take away, containing more detailed information on consequences of excessive drinking and tips for cutting down (this can be in a variety of media, including electronic, such as the internet)
- signposting individuals to having a wider general health check, where indicated arrangements for follow-up monitoring.[167]

NHS Scotland has developed specific guidance on screening and the delivery of alcohol brief interventions in the antenatal setting, outlining steps on how to approach the subject of alcohol consumption (**Figure 5**).[178]

Figure 5 – NHS Health Scotland, stages of screening and delivering an alcohol brief intervention

Stage 1 – Raise the issue
'The next area for us to focus on is alcohol use. While some women go off alcohol when pregnant, many continue to have an occasional drink. Are you drinking at the moment?'

Stage 2 – Screen and give feedback
'Can you take me through what you normally drink in a week?[...]on your heaviest drinking day during the week?' 'From what you've told me, you are drinking more than the current guidance for alcohol consumption during pregnancy... this means that the amount you are drinking is risky for your developing baby and also for your own health now and in the future.'

Stage 3 – Listen for readiness to change
'How do you feel about what we have discussed?'
'What would be helpful to you just now?'

Stage 4 – Choose a suitable approach
Information and advice – on the impact of alcohol on her own health, and evidence for the impact of alcohol on the developing fetus, clarify the current national guidance on drinking while pregnant.
Enhance motivation – build the woman's motivation to change by helping her to weigh up the pros and cons of her drinking.
Menu of options – for changing drinking behaviour. Ask the woman if she can suggest ways to change her drinking pattern (eg lower alcoholic-strength drinks, having drink-free days, taking up other activities). Be ready to offer ideas if the woman agrees.
Build confidence – using an interviewing style that enhances the woman's belief in her ability to change (her self-efficacy). For example, identifying her previous successes and role models she can learn from, and identifying other people who can support her.
Coping strategies – help the woman to identify times when she might find it more difficult to stick to her plans to cut down and to come up with strategies for coping with these situations.

Source: NHS Health Scotland (2015) Alcohol brief interventions: Antenatal professional pack. Edinburgh: NHS Health Scotland.

Antenatal care has been identified as a priority setting for the implementation of alcohol brief interventions in Scotland.[179] Despite this, a qualitative evaluation has indicated that limited numbers of women in Scotland are receiving brief interventions as part of antenatal care, and that competing workload pressures may be resulting in alcohol interventions being seen as low priority.[113] Public Health Wales has also introduced a programme of intervention training for midwives as part of a strategy aimed at reducing alcohol related harm. As of September 2012, under 15 per cent of Welsh midwives had received the training.

Healthcare professionals require sufficient consultation time for brief interventions to be carried out appropriately. To support alcohol brief interventions for women who are pregnant, further research is required to better understand their effectiveness and improve their delivery.

Recommendations

– Healthcare professionals working in antenatal care should be aware of guidance on the provision of brief interventions for those identified as drinking harmfully or hazardously. This should be supported by further research to assess the ongoing effectiveness of alcohol brief interventions for pregnant women.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government / National Institute for Health and Care Excellence / Scottish Intercollegiate Guidelines Network / UK Research Councils / National Institute of Health Research (England) / NHS Research Scotland / National Institute for Social Care and Health Research (Wales) / Alcohol Research UK.

– Healthcare professionals should be given sufficient time and resources to ensure that any woman who is pregnant, or who is planning a pregnancy, and who has a suspected or confirmed history of alcohol consumption at low-to-moderate levels is offered brief intervention counselling. This should occur at the earliest possible stage and be considered a part of routine antenatal care where required.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government / Royal College of Obstetrics and Gynaecology / National Institute for Health and Care Excellence / Scottish Intercollegiate Guidelines Network

– All healthcare professionals providing antenatal care should be trained in the delivery of brief interventions within this setting, as well as having appropriate time and resources to ensure they are carried out effectively.

Action relevant to: General Medical Council / Nursing and Midwifery Council / Medical Royal Colleges / Royal College of Nursing / Royal College of Midwives

5.3.4 Targeted prevention for 'at-risk' women

There is encouraging evidence related to the effectiveness of selective prevention strategies targeting high risk or pregnant women.[180] Where a woman is identified as being at high-risk of PAE, healthcare professionals have a responsibility to implement targeted intervention protocols. There is, however, no specific UK guidance on the delivery of targeted prevention for 'at-risk' women. Several innovative indicated prevention strategies have been trialled in the US (see **Appendix 7**). These prevention efforts target women at high-risk of PAE, including those with a history of alcohol misuse, those with severe alcohol problems, and women who have previously delivered a child affected by alcohol.[181,182] The Centre for Substance Abuse Treatment and the Substance Abuse and Mental Health Services Administration (within the US Department of Health and Human Services) has also produced treatment improvement protocols. These are best practice guidelines for the treatment of substance abuse and intended to stimulate a wide variety of service providers to participate in crafting a full continuum of family-oriented services for pregnant, substance-using women and their children.[183]

There is no evidence that brief interventions are effective among individuals with more severe alcohol problems and levels of dependence.[165] Referral to specialist alcohol services should therefore be considered for women who are dependent on alcohol and who are pregnant, or those trying to conceive. Specialised treatment services consist of therapeutic approaches (eg relapse prevention) and management components (eg detoxification facilities, inpatient residential programmes and outpatient clinics). NICE guidelines for pregnancy and complex social factors identifies substance misusers as one of four groups of pregnant women with complex social factors, and recommends appropriate standards of care including co-ordinated multi-agency care plans.[184] These guidelines recommend referring a woman who misuses alcohol to an appropriate substance misuse programme the first time she discloses she is pregnant. The guidelines also recommend that midwives and doctors should advise any pregnant woman who misuses alcohol, about relevant additional

services (such as drug and alcohol misuse support services) and encourage her to use them according to her individual needs.

Guidance on the referral and follow-up of patients with alcohol problems is outlined in *The management of harmful drinking and alcohol dependence in primary care* (SIGN, 2003),[168] although this does not provide specific guidance on problem drinking during pregnancy. NICE guidance on *Alcohol-use disorders: preventing harmful drinking* also provides advice on the diagnosis, assessment and management of harmful drinking and alcohol dependence in adults and is designed to complement existing NICE clinical guidance on antenatal care.[168]

Alongside targeted prevention, it is important that those cases where PAE has occurred are comprehensively followed up. To prevent secondary harm, children known to have been exposed should enter the diagnostic process and follow the pathways described in **Chapter 6**.

Recommendations

- Specific UK 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, including those with a history of alcohol misuse, those with severe alcohol problems, and women who have previously had a child affected by alcohol.

- Any woman who is identified as being at high-risk of prenatal alcohol exposure should be offered to specialist alcohol services for appropriate treatment. Any referral should be followed up and assessed at regular intervals.

- Children identified as having been prenatally exposed to alcohol should be followed up to ensure they enter the diagnostic process and follow the appropriate management pathway.

Actions relevant to: National Institute for Health and Care Excellence / Scottish Intercollegiate Guidelines Network / Royal College of Obstetrics and Gynaecology / Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government

Matthew's story...

I am one of the oldest known people with FASD diagnosed in the UK. FASD is a part of me and I have never known any different although I think I can see what 'normal' is, although there is no definitive answer to that. If there's a hard way to do things I usually take that route (schoolwork & employment). Get tired quite easily and quickly when bored. Also tire quickly if I have to concentrate hard on things that are unfamiliar to me. Find starting new tasks hard and have to be told more than once how to do things. Also forget and have to be retold everything. I get very nervous and scared inside. You don't want anyone's help with anything because you feel like a loser if you ask for it and won't understand what they're on about anyhow if they do try to help you. Continually judge myself when there's no need to creating a spiral effect that increases my anxiety. I can only think of one thing at a time in one direction. Feel, look and act much younger than I am. I fantasise about my life and often want to be the greatest person in the world. Take hours on one thing like an essay (get blocked don't know where or how to begin so just start waffling on hoping something might give me credit). I cannot read body language so am wary of other people but very friendly towards them at the same time. I imagine how people might be feeling towards me but get the wrong impression. Good long-term and poor short-term memory – can remember things like phone numbers and car registration plates from 20 years ago but can't remember who I met this morning or did I lock the car when I left it 30 seconds ago? I cannot necessarily remember people well though. On the outside you look normal but very few people have actually clicked with me as friends. Music helps to stimulate my brain and singing a lot makes me happy and produces adrenaline. I used to feel angry with my natural parents and still find relations with my father difficult but don't see my mother. I suffer from depression and from loneliness and due to this my vulnerability is increased leading to risky and frightening situations. Although I have had thoughts of suicide I am too strong to ever go through with it. Interactions with other people are hard although rarely feel bored when on my own due to obsessive behaviour. Government policy in the UK towards alcohol is shameful £1bn per year spent in the NHS alone due to binge drinking which could be used on other affairs if FAS awareness was increased.

Case study originally sourced for the 2007 version of this report

Chapter 6
Diagnosis and management of fetal alcohol spectrum disorders

6

Chapter 6 – Diagnosis and management of fetal alcohol spectrum disorders

The diagnosis and management of the range of FASD requires a multidisciplinary approach involving a wide range of healthcare professionals – including paediatricians, obstetricians, psychologists, GPs, neurologists, psychiatrists, clinical geneticists, health visitors and midwives – as well as individuals in the fields of education and social services.[3] Highlighting the need for further action in this area, the BMA 2015 ARM unanimously passed a resolution calling for improved services and referral pathways for the diagnosis, management and support of individuals and families affected by PAE.

6.1 Diagnosis

The timing of diagnosis is important, and usually occurs later in early childhood as brain damage or developmental delay may not be obvious in very young children, and CNS deficits are required for a diagnosis of FAS.[9,122] The difficulty of diagnosis is further complicated by the fact that many genetic and malformation syndromes (eg Williams syndrome, Cornelia de Lange syndrome, Velocardiofacial syndrome) have similar clinical characteristics to those found in the range of FASD.[82,185] The incidence of children affected by genetic and dysmorphic syndromes, other than FASD, is the same whether or not their mothers abused alcohol when carrying them.[82] Caution should therefore be used when diagnosing a child who presents the clinical characteristics to those found in the range of FASD, as the presenting phenotype may be caused by genetic and dysmorphic syndromes other than FASD. To this end there is a need to approach diagnoses of FASD as one of exclusion as well as inclusion. Genetic assessments have been shown to be of particular value in excluding other diagnoses, such as chromosome disorders, that share symptoms or phenotypes with FASD.[186] It is important that, when diagnosing FASD, healthcare professionals foster an environment that supports those affected, while avoiding blame, social stigmatisation and feelings of guilt in the parents.

To confound clinical diagnosis further, children affected by PAE may also have another genetic syndrome as a comorbidity. Diagnosis in adults is particularly challenging as physical features may change over time, there may be catch-up growth, and cumulative environmental influences may distort the evaluation of brain function. Obtaining reliable information on the adult's history and abilities may also be difficult, and may be complicated by factors including alcohol and drug abuse, and mental health problems. Diagnosis of the range of FASD therefore requires skilled clinical differentiation and a good understanding of the nature of FASD and the diagnostic techniques involved in identifying the range of conditions.

A complete maternal history is also an important component in FASD diagnosis as it provides information on maternal factors that are associated with an increased risk of FASD (eg a history of alcohol and/or other substance abuse[i], a previous child with FASD).[9] Information on these maternal factors can be extremely valuable, if not essential, in FASD diagnosis, especially when there is no confirmed history of maternal alcohol use, or when infants show only a few signs or symptoms of PAE. Stigma and fear of judgment may discourage women from disclosing to healthcare providers that they drank during their pregnancy. Training is therefore required in how to obtain this information in a non-threatening and non-judgemental manner.

Formal diagnosis at the earliest possible stage is paramount as it permits the implementation of early intervention and treatment programmes. Early diagnosis can also decrease the risk of additional problems commonly found in individuals affected by these

i The American Academy of Pediatrics has summarised the impact of prenatal exposure to different drugs on a range of outcomes (Behnke, M & Smith, VC (2013) American Academy of Pediatrics technical report. Prenatal substance abuse: short- and long-term effects on the exposed fetus. *Pediatrics*, **131**(3), e1009–24).

disorders that result from the neurocognitive deficits (eg psychiatric problems, disrupted school experience, trouble with the law, and alcohol and drug problems).[3,9] An early diagnosis is crucial to the provision of support and a better overall outcome for an individual with FASD. Inadequate diagnosis and support of FASD can lead to a far greater chance of secondary comorbidities for the individual, including mental health issues, crime and incarceration, sexual inappropriateness, substance abuse, and educational difficulties.[122,187]

"The potential for learners with FASD is variable but [their] potential can be fulfilled if the environment for teaching and learning is correct. We have seen significant improvement in pupils with FASD and enjoy their success and increased skills, fitting them for life in the wider community. The earlier the diagnosis the earlier support networks can be put in place and learning maximised".

Celia Dawson
Headteacher: Cricket Green School (for special needs pupils)
Originally included in the 2007 version of this report.

The range of FASD are commonly under-diagnosed reflecting a number of factors including:
- the lack of a specific diagnostic test
- an under-reporting of maternal alcohol consumption, or lack of maternal alcohol history
- the difficulty in detecting the defining features associated with FASD in neonates
- confounding factors (eg poor nutritional maternal status or polydrug use)
- differing and poorly defined diagnostic criteria for FASD
- the lack of multidisciplinary neurodevelopmental teams to complete comprehensive assessments needed to evaluate the full range of FASD.

A lack of knowledge and understanding of FASD among healthcare professionals also means they often may not feel competent to make a diagnosis.[9,21,188,189] Variation in knowledge and awareness poses a significant challenge to the implementation of a comprehensive and consistent approach to the management of FASD.

6.1.1 Developing diagnostic guidelines for fetal alcohol spectrum disorders

In common with other disorders (eg common psychiatric disorders), there are no specific single diagnostic tests or biomarkers for FASD. Diagnosis can still be made based on assessment of all aspects of the clinical criteria through inclusion and exclusion. A multidisciplinary approach to FASD diagnosis is therefore required to ensure that it is possible to understand the presentation of, and test for, other diagnoses. It is therefore important that the diagnosis of FASD is supplemented by evidence to exclude other factors through genetic testing.[192]

Diagnostic criteria for FAS are well established, and based on three facial features, pre and postnatal growth deficits, and neurocognitive deficits.[122] FAS can be diagnosed with or without confirmed maternal alcohol exposure. The diagnostic criteria for prenatal alcohol-related conditions other than FAS are however less precise and remain poorly defined due in-part to a lack of available scientific evidence.[21,190] The IoM (Institute of Medicine) was the first to publish recommended diagnostic guidelines for FASD in 1996.[j] Since then several other sets of diagnostic criteria have been developed, including the CDC (Centers for Disease Control and Prevention) criteria, the 4-Digit Diagnostic Code, and the Canadian FASD guidelines (see **Appendix 2**). The criteria used vary within, and between countries, and many clinics use combinations of criteria, or their own adaptations.[21,191]

In the UK, there are no formal FASD diagnostic guidelines. A meeting of health professionals in the UK in 2011 – facilitated by a national FASD charity, the FASD Trust – agreed that the Canadian guidelines on diagnosis as set out by Chudley et al in 2005 (**Figure 6**) should be adopted in the UK, as they combine the best of the other two main methods (the IoM guidelines and the 4 digit code).[123] The BMA supports this approach. These guidelines are

j The IoM guidelines were revised in 2005 and are commonly known as the Hoyme diagnostic guidelines.

under revision by the Canadian Fetal Alcohol Spectrum Disorder Research Network, to clarify diagnostic terminology for FASD.[192] The updated guidelines will include the diagnosis of FASD with and without facial dysmorphology. Criteria for ND-PAE – set out by the APA in 2013 – also allow diagnosis with and without facial characteristics (Appendix 2).[4] It will be necessary for the continued relevance of these guidelines – including any revisions – to be monitored and reviewed in the UK context, as well as the impact of other guidance, including the APA's proposed criteria for diagnosing ND-PAE.

Figure 6 – Canadian guidelines for diagnosis

The Canadian guidelines for diagnosis of FASD, published in 2005[k] were developed as a result of a Canadian-government funded review and analysis of the approaches to diagnosis that existed at the time, and are based on the widespread consultation of experts in the field.[193] The guidelines place an emphasis on making the diagnosis of FASD one of exclusion, and full exploration of other possible causes of symptoms and phenotypes.[194] They outline the following six key areas to be addressed during the diagnostic process:

1. screening and referral
2. physical examination and differential diagnosis
3. neurobehavioural assessment
4. treatment and follow up
5. maternal alcohol history
6. diagnostic criteria for FAS, PFAS and ARND.

The full Canadian guidelines for diagnosis are set out in **Appendix 2**. Because of the complexity of FASD the Canadian guidelines recommend a multidisciplinary approach to diagnosis.

In developing and implementing guidelines for the diagnosis of FASD, it is important to recognise that a range of technological advances may – in the future – provide the basis for more specific and accurate diagnosis of FASD. These include diffusion tensor magnetic resonance imaging, which has been used to detect subtle abnormalities in individuals with FASD by measuring white matter and structural integrity in the brain.[195] Eye movement assessment has shown that children with FASD have more saccadic eye movement[l] deficits, including longer reaction times and direction errors, which may prove to be a useful tool in diagnosis.[194] Three dimensional facial imaging has also been shown, in limited studies, to be highly accurate at detecting FAS facial abnormalities.[196,197,198]

Recommendation

– Guidance on the diagnosis of the full range of fetal alcohol spectrum disorders should be developed and made available to all healthcare professionals throughout the UK. This should be based on the Canadian diagnostic guidelines as a model of best-practice, as well as acknowledging new criteria set out by the American Psychiatric Association for the diagnosis of neurobehavioural disorder associated with prenatal alcohol exposure. Guidance on diagnosis should emphasise the need for testing to exclude other disorders.

Actions relevant to: National Institute of Health and Care Excellence / Scottish Intercollegiate Guidelines Network / Royal College of Obstetrics and Gynaecology / Royal College of Paediatrics and Child Health / Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government.

k As of November 2015 these guidelines were under review by the Canadian Fetal Alcohol Spectrum Disorder Research Network.

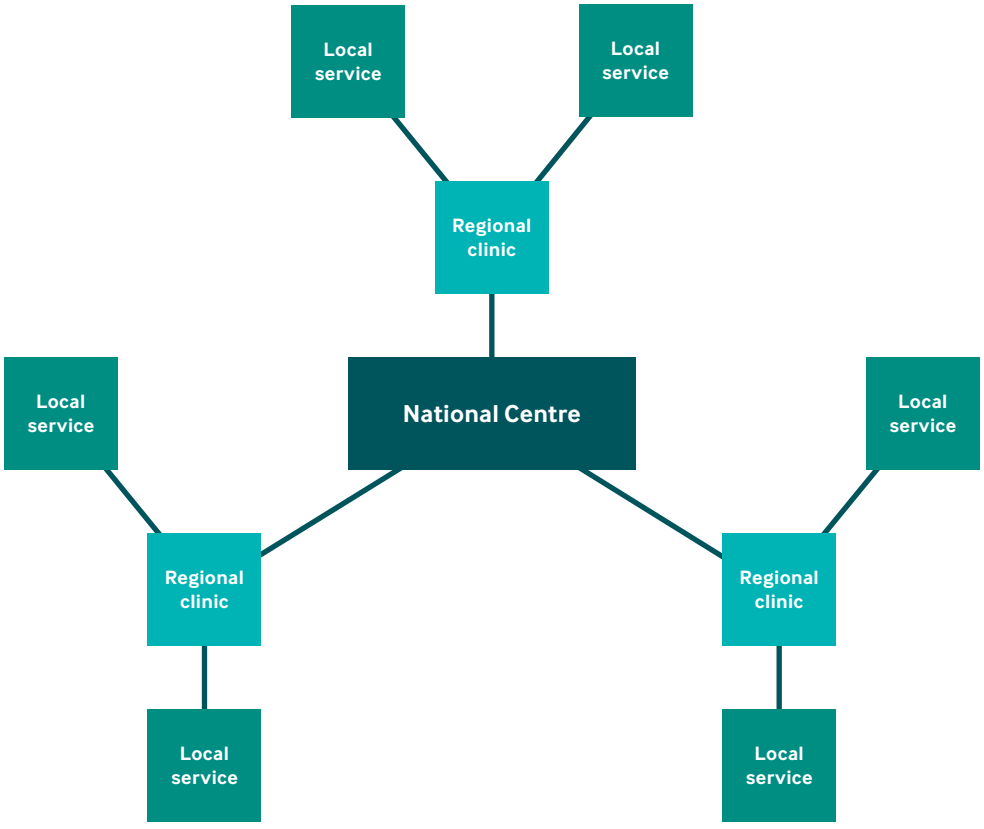
l Saccidic eye movements are quick simultaneous movements of both eyes, allowing them to allowing them to accurately refix on an object in the visual field.

6.2 Referral pathways and specialist services for fetal alcohol spectrum disorders

As the Canadian guidelines set out, the diagnosis of FASD requires a multidisciplinary approach.[193] FASD is commonly diagnosed in secondary care, however there is no clear pathway in the UK for the referral of individuals with suspected FASD to specialist services, to allow a complete diagnostic evaluation. Nor are there adequate specialist services to support these referrals.[123] There is inconsistency in where individuals are referred; and the services to which they are referred may not necessarily have the skills required to diagnose and manage FASD effectively. The development of clear referral pathways and provision of adequate specialist services for the comprehensive diagnosis and subsequent management of FASD needs to be addressed urgently. This should be supported by a national framework for the organisation of FASD services.

While there is a specialist national clinic, and some individual clinicians with an interest in FASD, there are no established networks of care in the UK for individuals affected by PAE. A basic model for FASD service delivery has been proposed (**Figure 7**).[199] This model is structured around a single national centre containing a multidisciplinary team, and supporting regional clinics in secondary care that include clinicians with expertise in FASD. Local health services, including primary care, have responsibility for supporting referral to specialist services and helping families access appropriate resources. The aim of this model of service delivery is to ensure wider access to specialist services for diagnosis, and improved access to expertise on the management of FASD for those affected.[199] The use of such a service model – based around a national centre supporting regional clinics – is in line with well-established models in other disciplines, and is also designed to facilitate the dissemination of expertise from the national level, via regional services, to local clinicians. This basic model may be appropriate for England, but some modification would be necessary to make it fit for the NHS in the other three nations of the UK, taking into account the difficulties in arranging care for patients in UK national centres who live in one of the other three nations.

Figure 7 – Proposed basic model for national FASD service delivery



Courtesy of Dr Raja Mukherjee Surrey and Borders Partnership NHS Foundation Trust.

To address the lack of clear pathways for the referral of individuals with suspected FASD, a consensus group of UK medical professionals with expertise in FASD have developed proposals for specific care pathways across the UK. These include setting out the process – in perinatal care – that should lead to referral of individuals to specialist services for comprehensive evaluation and diagnosis (**Figure 8A**).

The group have also set out a process of follow-up for individuals with a high risk of PAE, who have not demonstrated clear features of FASD. This is designed to ensure individuals are referred to appropriate specialist services for comprehensive evaluation if symptoms of FASD become apparent in the future (**Figure 8B**).

Figure 8A – Proposed perinatal care pathway

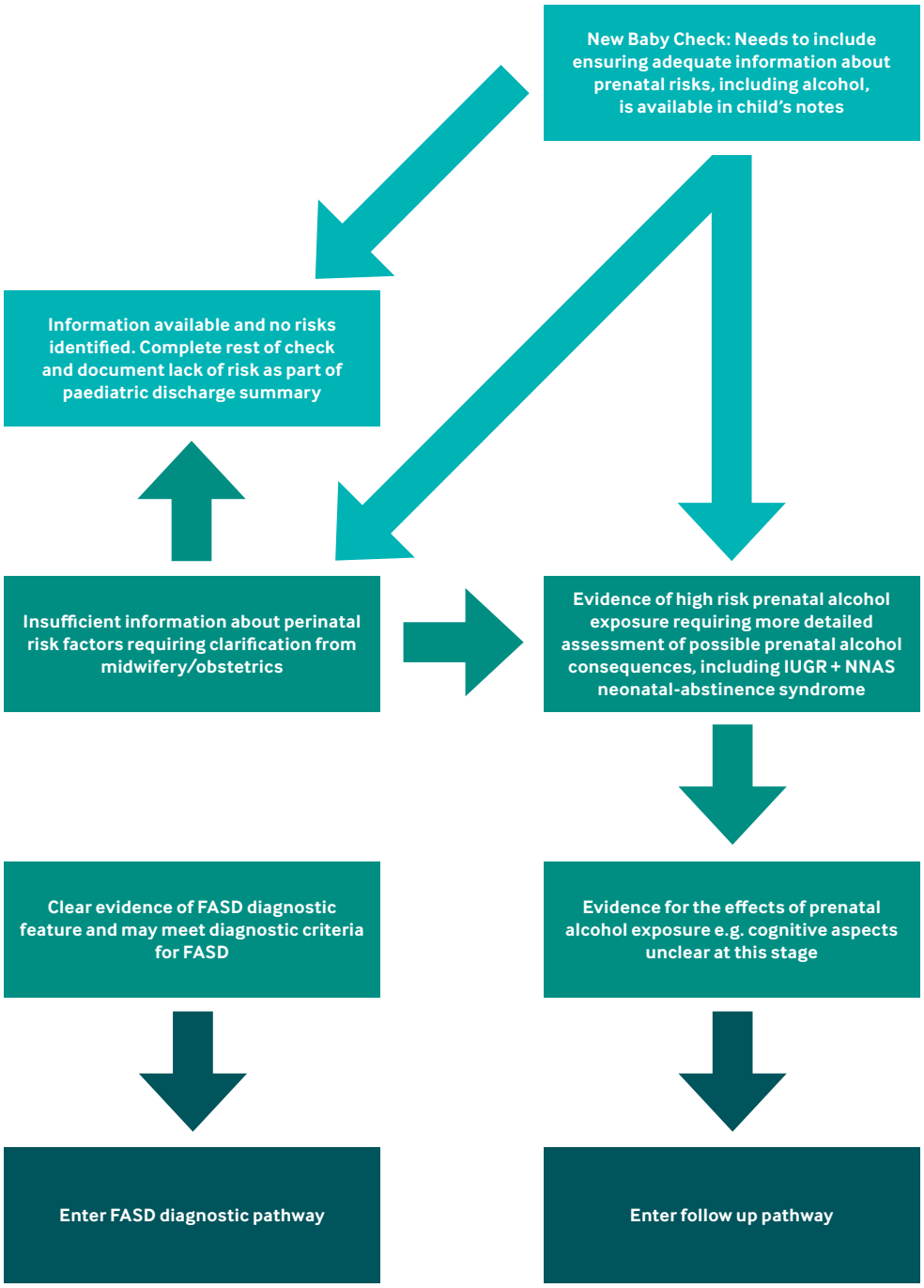


Figure 8B – Follow-up pathway

Source: Mukherjee RAS et al (2013) Consensus statement regarding the recognition and diagnosis of foetal alcohol spectrum disorders across the lifespan in the UK: Development of proposed UK clinical pathways. Oxfordshire: The FASD Trust.

6.2.1 Commissioning and funding of services

Adequate funding is required for the development and maintenance of specialist services throughout the UK, to support the referral of individuals affected by PAE. It is important that this includes the commissioning of specialist FASD services; in the UK there is no specific commissioning of services for the diagnosis and management of FASD. The National Clinic for Fetal Alcohol Spectrum Disorders – the only specialist FASD behavioural clinic of its type in the UK[200] – relies on IFRs (individual funding requests), whereby clinicians in England have to apply to their local CCG for funding in order to refer individual patients. The lack of proper commissioning acts as a barrier to the development of services required to adequately address the needs of individuals affected by PAE. To support the commissioning of specialist services, better epidemiological data on the incidence and prevalence of the range of FASD in the UK is required, as discussed in **Section 2.1**.

Recommendation

– Diagnostic and referral services for FASD should be commissioned and adequately resourced throughout the UK. There should be sufficient funding for the development, training and maintenance of multidisciplinary diagnostic teams and clear pathways established for the referral of FASD across the UK.

Actions relevant to: National Institute of Health and Care Excellence / Scottish Intercollegiate Guidelines Network / Royal College of Obstetrics and Gynaecology / Royal College of Paediatrics and Child Health / Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government.

6.3 Clinical management

There has been limited research into the clinical management of FASD,[3,194] and there are no frameworks for its clinical management in the UK. After the birth of a child who has FASD there are essentially two targets for intervention: the mother and the child. Each is in need of care to treat and improve their health as well as to prevent the birth of another FASD child. Often FASD-affected children are placed in foster care because of neglect or abuse. As such, a key reason for improving the social and health position of the mother is so that she can continue or regain care of her child(ren) as well as taking care of her health.

It is important that diagnosed individuals and their families are linked to appropriate resources and services. To support this a comprehensive framework for the clinical management of FASD in the UK needs to be developed. Effective clinical management requires the implementation of postnatal interventions and the cooperation between a wide range of healthcare professionals including GPs, obstetricians, paediatricians, psychiatrists, psychologists, and speech and language therapists (see **Appendix 8**).[3] Further management requires specialist support in the provision of education and social services. The adverse effects of PAE on learning and life skills varies significantly among individuals, thus management programmes have to be tailored to the individual and his or her family. There is evidence to suggest that improvements in social skills, improved executive-functioning, and reductions in problem behaviour can follow specialist training and interventions in children with FASD.[201,202] Early recognition and management of the disabilities associated with FASD may help reduce the overrepresentation of this group within the criminal justice system.

Social services may be required to ensure a supportive and stable home environment and to provide parental education. Educational support is essential during schooling years and requires adequately trained school staff. Information and classroom support sheets have been produced by The Schools Network, which aim to provide clear guidance for teachers on the characteristics of children with FASD.[203] The provision of adequate social care and educational support is dependent on sufficient funding from local authorities and local education authorities respectively. For intervention programmes to be effective, they need to be focused on an individual's developmental level. Intervention strategies for school-age children need to focus on providing specialised educational opportunities; whereas interventions for adolescents should also focus on providing vocational and transitional services (eg employment skills). It is important that healthcare professionals work closely

with education and social service providers to ensure that individuals affected by the range of FASD are appropriately assessed in terms of their communication and social skills, emotional maturity, verbal and comprehension abilities, language usage, and healthcare requirements. These assessments should be used to inform the clinical management programme. It is also important that healthcare professionals provide information on the available support services to carers and their families.

Recommendation

A framework for the clinical management of individuals affected by the range of fetal alcohol spectrum disorders, as well as their birth mothers, should be developed and adequately resourced.

Action relevant to: Department of Health (England) / Department of Health, Social Services and Public Safety (Northern Ireland) / Scottish Government / Welsh Government / National Institute for Health and Care Excellence / Scottish Intercollegiate Guidelines Network

Chapter 7
Conclusion

7

Chapter 7 – Conclusion

The range of FASD are a significant health consequence of maternal alcohol consumption and can cause immense distress and lifelong personal difficulties to those affected. PAE represents a substantial public health concern, and FASD are a significant burden on resources in the health and social care sector, as well as the education and justice systems. The effects of PAE are complex and can range from mild cognitive impairment to the full presentation of FAS that is characterised by facial dysmorphology, growth deficiencies and neurocognitive deficits. The full range of disorders is not adequately recognised either in the UK or internationally. While FAS is widely accepted as a clearly diagnosable disorder, the clinical features of other forms of FASD including PFAS, ARND and ARBD are less well defined and subject to considerable debate. As a consequence, the epidemiology of the full range of disorders is not accurately known. ND-PAE, a clarifying term has been proposed by the APA.[4] Diagnostic criteria developed for ND-PAE are designed to encompass the full range of developmental disabilities associated with prenatal exposure to alcohol.

In the UK, data on the incidences of FASD are extremely limited, and are restricted to FAS. Available international data suggest that some populations, including those which experience high degrees of social deprivation and poverty, are more likely to have children affected by the range of FASD.[25,27,29,32,33] Higher rates of FASD have been estimated among children in foster care, and those in correctional systems.[28] It is vital that efforts are made to establish the epidemiology of the range of FASD in the UK through an increased recognition of these disorders and improved data collection.

Accurate information regarding the risks of alcohol consumption during pregnancy is necessary for the implementation of health promotion and prevention strategies. While the exact mechanisms of alcohol teratogenesis are not fully established, it is clear that heavy maternal alcohol consumption can adversely impact on fetal development and lead to significant postnatal and long-term problems for the child. The occurrence of FAS has been found to be strongly associated with heavy maternal alcohol use – particularly in cases of alcohol dependence or severe alcohol problems – and with the frequency of heavy dose drinking.[8,9,25,72] These findings are significant given the substantial number of women of childbearing age in the UK who engage in heavy and/or binge drinking, and the frequency of unplanned pregnancies. The causal relationships between maternal alcohol consumption and other FASD are less well understood. It is clear that individuals affected by PFAS, ARBD and/or ARND exhibit some, but not all, of the anomalies found in individuals affected by FAS. Research has shown there to be critical periods of fetal development that are particularly sensitive to the effects of PAE at heavy doses.[3,8,9,67] It has been suggested that specific anomalies associated with FASD may result from exposure to heavy doses of alcohol during specific periods of fetal development whereas FAS results from exposure to heavy doses throughout a pregnancy.[72]

There is considerable debate as to the adverse effects of PAE at low-to-moderate levels as the existing evidence is inconclusive. This has led to variation in the emphasis of guidance and advice on alcohol during pregnancy. In light of the uncertainty in this area, the BMA believes that, on balance, the safest advice to women should be to avoid alcohol consumption entirely during pregnancy. This would provide a clear, unequivocal public health message and also reflects that limits on consumption can be misinterpreted, as individuals may not clearly understand what units or 'standard drinks' are.

Preventing the adverse impact of alcohol consumption during pregnancy remains a significant challenge, not least because of the poor levels of awareness and understanding of FASD among healthcare professionals and the general public. It is important to recognise that maternal alcohol consumption takes place in the context of alcohol being a normal part of everyday life in the UK.

To reduce alcohol consumption during pregnancy therefore necessitates broader regulatory measures that alter drinking behaviour at a population level. Controlling the accessibility, availability and promotion of alcohol needs to be considered as part of any public health strategy aimed at reducing alcohol consumption. The use of health promotion and educational programmes have, on their own, been shown to be ineffective at altering

drinking behaviour and must therefore be considered as part of a wider alcohol-harm reduction strategy. Primary and community care settings provide the ideal opportunity to deliver selective prevention strategies including screening for maternal alcohol consumption and referral for brief intervention. Healthcare workers in these settings need to be supported with adequate time, resources and guidance in order to deliver effective preventative strategies. Targeted prevention strategies for women who are at high-risk of having children affected by FASD include treatment of alcohol addiction problems (ie referral to specialist alcohol services) and family planning advice so as to prevent the risk of having a FASD affected child.[183] A co-ordinated, inter-agency approach is required to improve service delivery to individuals with FASD and at risk women.

The management of FASD incorporates the identification, referral, diagnosis and treatment of individuals affected by prenatal exposure to alcohol. Early diagnosis is vital to ensure appropriate treatment and support systems are implemented at the earliest stage. The lack of knowledge and understanding of FASD among healthcare professionals means they often do not feel competent to make a diagnosis. This is compounded by the absence of validated diagnostic or screening tools, the under-reporting of maternal alcohol consumption, the difficulty in detecting the defining features of FASD, and the similarity between the characteristic features of FASD and other genetic and malformation syndromes. As a consequence, FASD is rarely diagnosed at birth or in infancy. There is a lack of specific guidance on diagnosis, referral and treatment in the UK, although clinical care pathways from antenatal care to diagnosis have been proposed by a forum of UK health and medical professionals. Several sets of diagnostic criteria have been developed to assist in the evaluation and categorisation of the effects of PAE. Clear guidance on the diagnosis of the full range of fetal alcohol spectrum disorders, for all healthcare professionals in the UK, is required. A greater emphasis is needed on the clinical management of individuals affected by FASD through further research and the development of appropriate guidance. Treatment for FASD requires the implementation of tailored management programmes and specialised support in the provision of healthcare, education and social services.

An increased awareness among the general public and healthcare professionals, together with effective universal prevention strategies and improved clinical guidelines for the prevention and management of FASD, are important measures in tackling this ongoing concern.

Recommendations

Epidemiology of fetal alcohol spectrum disorders

– Data on fetal alcohol syndrome should be routinely collected throughout the UK and consideration given to how this should extend to cover the range of fetal alcohol spectrum disorders.

– Further research should be undertaken to establish the epidemiology of the range of fetal alcohol spectrum disorders in the UK. This should be supported by the implementation of uniform diagnostic criteria and improved data collection, and should include a meta-analysis of existing data, as well as coordinated large scale population-specific prevalence studies. As passive surveillance studies may underestimate prevalence of fetal alcohol spectrum disorders, future research should include active case ascertainment studies.

Understanding the effects of alcohol consumption during pregnancy

– Further research should be undertaken in the UK to examine the relationship between prenatal alcohol exposure and the range of conditions associated with fetal alcohol spectrum disorders. Future epidemiological studies specific to fetal alcohol spectrum disorders should be based on whole populations and include a range of measures in order to differentiate outcomes between different groups.

– Further research should be undertaken to clarify the exact mechanisms of alcohol teratogenesis and establish how they relate to the pattern of anomalies associated with fetal alcohol spectrum disorders.

Improving awareness of fetal alcohol spectrum disorders in the medical profession

– Training programmes for healthcare professionals on the prevention, diagnosis and management of the range of fetal alcohol spectrum disorders should be implemented in the UK. Training on fetal alcohol spectrum disorders should also be provided for those working in the fields of social work, criminal justice and education.

– Training on the prevention, diagnosis and management of fetal alcohol spectrum disorders should be integrated into undergraduate and postgraduate curricula and continued professional development.

Prevention of fetal alcohol spectrum disorders

Guidance on alcohol consumption in pregnancy

– Women who are pregnant, or who are considering a pregnancy, should be advised that the safest option is not to consume any alcohol. Relevant stakeholders should work in partnership to ensure guidance and advice on alcohol and pregnancy is consistent and clear.

Universal prevention strategies

– Alcohol policy should focus on reducing overall consumption in the population, through a range of regulatory and policy measures including:
  – increasing excise duty on alcohol above inflation
  – implementation of The Alcohol (Minimum Pricing) (Scotland) Act 2012, and support for legislation to introduce minimum unit pricing in all four nations of the UK
  – reductions in licensing hours for on- and off-licensed premises
  – a comprehensive ban on all marketing communications.

– Measures to reduce the accessibility, availability and promotion of alcohol should be complemented by steps to increase public awareness of the risks of drinking during pregnancy, supported by mandatory labelling of alcoholic products that highlight the health risks of alcohol consumption during pregnancy.

– High quality alcohol education programmes that include information on the risks of drinking whilst pregnant should be provided in schools throughout the UK.

Health promotion and advice

– Healthcare professionals should be supported with the necessary time, resources and guidance to ensure that they are able to provide advice and support to expectant mothers at every stage of pregnancy on the risks of maternal alcohol consumption, when clinically appropriate.

Monitoring and detecting maternal alcohol consumption (screening)

– Adequate time, resources, training and guidance should be provided to healthcare professionals involved in the provision of antenatal care to:
  – allow screening for maternal alcohol consumption – via objective techniques such as T-ACE, TWEAK and AUDIT-C – to form part of routine antenatal care in the NHS
  – ensure that alcohol use among pregnant women is monitored and recorded appropriately.

– Further research should be undertaken to examine the most effective screening methods for assessing maternal alcohol consumption.

Brief interventions

– Healthcare professionals working in antenatal care should be aware of guidance on the provision of brief interventions for those identified as drinking harmfully or hazardously. This should be supported by further research to assess the ongoing effectiveness of alcohol brief interventions for pregnant women.

– Healthcare professionals should be given sufficient time and resources to ensure that any woman who is pregnant, or who is planning a pregnancy, and who has a suspected or confirmed history of alcohol consumption at low-to-moderate levels is offered brief intervention counselling. This should occur at the earliest possible stage and be considered a part of routine antenatal care where required.

– All healthcare professionals providing antenatal care should be trained in the delivery of brief interventions within this setting, as well as having appropriate time and resources to ensure they are carried out effectively.

Targeted prevention for 'at-risk' women

– Specific UK 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, including those with a history of alcohol misuse, those with severe alcohol problems, and women who have previously had a child affected by alcohol.

– Any woman who is identified as being at high-risk of prenatal alcohol exposure should be offered to specialist alcohol services for appropriate treatment. Any referral should be followed up and assessed at regular intervals.

– Children identified as having been prenatally exposed to alcohol should be followed up to ensure they enter the diagnostic process and follow the appropriate management pathway.

Diagnosis and management of fetal alcohol spectrum disorders

– Guidance on the diagnosis of the full range of fetal alcohol spectrum disorders should be developed and made available to all healthcare professionals throughout the UK. This should be based on the Canadian diagnostic guidelines as a model of best-practice, as well as acknowledging new criteria set out by the American Psychiatric Association for the diagnosis of neurobehavioural disorder associated with prenatal alcohol exposure. Guidance on diagnosis should emphasise the need for testing to exclude other disorders.

– Diagnostic and referral services for FASD should be commissioned and adequately resourced throughout the UK. There should be sufficient funding for the development, training and maintenance of multidisciplinary diagnostic teams and clear pathways established for the referral of FASD across the UK.

– A framework for the clinical management of individuals affected by the range of fetal alcohol spectrum disorders, as well as their birth mothers, should be developed and adequately resourced.

Janet's story...

In 1978 our family fostered Matthew. He was four months old when he arrived at our home. His family had been under supervision due to his mother's bouts of alcoholism. After his birth the mother's drinking continued and Matthew and two older children were taken into care, Matthew was two weeks old. Matthew was a very sickly, quiet baby, he never cried. He was a very difficult feeder, very withdrawn, no smiles, no expressions; looking back at my notes I see that he first laughed when he was over a year old. Matthew was diagnosed with FAS in July 1978, also a heart murmur, suspect clicky hips and flat feet. We were told that Matthew was backward and would never live a normal life. He was unable to sit up unsupported until over two years old, walked at around four years old and was only out of nappies a matter of weeks before he started school. He hardly spoke and an intensive programme to improve his language was initiated at around three years old. Matthew was a very small, vulnerable timid child. He had a small head, no body fat, indistinct features, bad coordination, poor eyesight, fragmented vision in one eye, teeth in unusual places and he hated loud noises. He also had difficulty in sleeping, was hyperactive and prone to infections – we loved him. Matthew's play was obsessive, lines of stones, circles with string, swinging on the swing for hours whilst blowing a whistle and an extremely deep interest in windscreen wipers. When Matthew was five he attended the local primary school, he was a very lonely and frightened little boy, no friends and isolated in the playground. He suffered agonies away from home and constantly sucked his thumb. If there was statementing at his school we were never offered it. Matthew's first teacher at school, seeing his distress and isolation at playtimes, took him into the classroom and taught him to read which was a great achievement for Matthew. Once Matthew had learnt to read and write his obsessive play changed, he made lists, hundreds of them. The opportunity came to adopt Matthew when he was seven. Matthew continued on with his education, in some areas he appeared bright, in others no ability at all and no aptitude for any sport. Fantasy was second nature to Matthew and this is something that continues to this day. At eleven he started at the secondary school which was a nightmare for him. I used to have to walk him to school as he was unsure of the way and leave him at the corner by the school. He was very lost and confused and lonely. He was unable to find his way around the school and not finding the toilets for several days.

Matthew is very stoical and endured his days there. He experienced a breakdown or a form of panic attack when he was 12 and a Social Services Counsellor was called in by the school. My husband's job sent us to Hong Kong when Matthew had turned 12 and we were there for almost four years. This was a mainly successful time for Matthew. I have read that there is a learning opportunity for children with FASD around the age of 13 and so this proved with Matthew. He attended an international school and learnt much which he still enjoys today. From the ages of 13 to 16 he learnt to canoe, bike ride round the territory, sing in a choir, become involved in stage management, improve his swimming and gain three GCSEs. He really loved his time there and achieved much although during our stay he saw a psychiatrist and had counselling for inappropriate behaviour. One of the findings from these sessions was his inability to recognise body language and facial expressions. Throughout his teens we always had to remind Matthew to shave, wash, change clothes etc. He had a checklist on his bedroom door to consult before he left in the morning. Sleep patterns were still poor and he slept with the radio on and still does. He achieved much but almost always took the more difficult route. He worked very hard and achieved a BTEC in Performing Arts. Obviously it was difficult for Matthew to work in stage management; jobs were few and far between and he was also very immature for his age. He got himself a six month web design course where he was paid a small salary. He was saving for driving lessons as he needed a British driving licence; his main ambition was to drive. He was still lonely, craving excessive physical contact, hugs and kisses something which had been ongoing his whole life; also when troubled he developed a childlike voice, and sucked his thumb.

At the age of 22 years old it was felt the time had come for Matthew to begin to live on his own with support from his parents. He began a new job and together we found him a room in a house, from there he biked to his job. It was a very difficult time for Matthew, difficulty with time keeping and trying to understand his job and live away from the family. Matthew was always good with money, he wouldn't starve although when the supermarket layout was altered he came home without any food and eventually I discovered this and had to go with him and show him the new layout; it's all these little complications that make life difficult for him. It soon became clear that Matthew couldn't cope with his job, the inability to begin

new tasks and poor social skills all contributed to this. We had also at this time sought help from the Social Services. It was difficult to get any help as Matthew didn't seem to fall within any category. No one seemed to have any idea of the needs of a young adult with FASD. Finally appointments were made for Matthew to see a consultant psychiatrist for learning difficulties. Also an occupational therapist, who carried out some very valuable sessions with Matthew teaching him how to read body language and facial expressions from photographs. Work continued to be a problem, he was given less to do as he made mistakes, his self esteem was low and he was feeling ill from the Seroxat. Matthew is very determined, he wanted to feel well so with advice from his GP he gradually reduced his dosage over a period of months until he was off them completely. Work was not improving and we were at a loss as to how to advise him, we feared that if Matthew became unemployed he would be at risk.

The disability job adviser tried to help but nothing improved. I can't tell you how many agencies I have sought help and advice from over the years without any results, most not having any idea what I am talking about. He was unhappy and lonely, spent a large amount of time sleeping. He had previously gone into chat rooms on the internet and we had warned him of the dangers of this. Suddenly Matthew seemed busy and more content, we should have been warned. Then we received a phone call from Matthew saying he was being blackmailed for £5,000. He had become involved via a chat room with a young man who, unbeknown to him, was a drug addict. After a few weeks of supposed friendship he demanded money with threats to harm Matthew. This culminated in the young man forcing his way into Matthew's flat. Matthew had been beaten up, held at knife point, handcuffed and sexually assaulted throughout the night. Matthew had stayed calm, managed to escape, called the police and seen the young man arrested. Matthew had several vulnerable persons interviews with the police, his father accompanied him. All this agony for Matthew is because he is lonely, can't read body language, has low self esteem and is immature for his age, this is due to FASD. Due to this assault Matthew had to move flats and now he has a quiet flat in a complex with an alarm call. The Social Services found this for him.

Matthew passed his driving test after six attempts and he bought a car. This has made a big difference to Matthew, he is now independent, he drives everywhere. His job had become non-existent; he was bullied and sworn at. We went to see a new young GP who he knew about FASD, the first time we haven't had to explain anything. The next question was whether his job was supported. He treated Matthew for depression and gave him sick leave and then, later put him on incapacity benefit; he shows great interest in Matthew and wants to help him. After a month's wait we saw the disability job adviser, and was offered a course aimed at getting him back into work. He could attend at his own pace, he would be assessed and suitable employment would be found for him and he would be supported within the workplace. He is now 29 years old and he is hopeful. As Matthew said once he had left his job, 'Maybe it's all for the best Mum' what amazing young people they are with FASD. I always speak the truth to Matthew, I tell it as it is. It can be painful and difficult for both of us but it must be so. I have always tried to stand back and let Matthew go, he sometimes makes mistakes, so do I. He's only just beginning to grow into his age. The one thing that worries my husband and myself is the lack of a circle of support for Matthew outside the family, very necessary as we get older and eventually die. I have nothing but admiration for Matthew, he has had many hurdles to climb, dreadful things have happened to him but he just picks himself up and tries again. He is a survivor; at last his head is up, he now stands straight. His father and I are very proud to be his parents.

Case study originally sourced for the 2007 version of this report.

Further information

Further information

Please note: *this listing of organisations and publications is intended for further information only. The BMA is not responsible for the content or accuracy of external websites, nor does it endorse or otherwise guarantee the veracity of statements made in non-BMA publications.*

FASD organisations

NOFAS-UK (National Organisation on Fetal Alcohol Syndrome)

www.nofas-uk.org

NOFAS-UK promotes public awareness about the risks of alcohol consumption during pregnancy with the goal to reduce the number of babies being born with FASD. It further acts as a source of information to the general public, press and to medical professionals.

NOFAS-USA (National Organisation on Fetal Alcohol Syndrome)

www.nofas.org

NOFAS seeks to create a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with FASD.

NOFAS Circle of Hope

www.nofas.org/circleofhope/

The NOFAS Circle of Hope peer-mentoring program works to reduce the stigma birth mothers face by connecting them with other women who have the same experience.

FASD Trust

www.fasdtrust.co.uk

The FASD Trust provides support for those affected by FASD and training / information for the professionals seeking to support them. It runs support groups for those affected by FASD across the UK, hosts various professional forums and has a variety of training and other resources for those affected by or interested in FASD.

FASD Scotland

www.fasdscotland.com/

FASD Scotland offers information, support and advice on FASD.

FASD clinic, Surrey and Borders NHS Foundation Trust

www.fasdclinic.com/resources

This clinic has developed a resource page for families and professionals including a series of video blogs explaining aspects of FASD.

EU FASD Alliance

www.eufasd.org/

The European FASD Alliance was founded in 2011 to meet the need for European professionals and NGOs concerned with FASD to share ideas and work together.

FASD Network UK

www.fasdnetwork.org/

FASD Network UK is a social enterprise providing support to caregivers of children and adults with FASD. It also provides training for professionals and practitioners and advocates for services for people with FASD.

EU Birth Mothers Support Network

www.eurobmsn.org/default.html

The European Birth Mother Network - FASD is a network of women who consumed alcohol during pregnancy and may have a child or children with FASD. The network offers a place where mothers can share their experience and support each other.

Learning resources for healthcare professionals

- NHS Education for Scotland Fetal Alcohol Harm e-learning resource (Accessible at www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/fasd)
- NOFAS-UK online course on Fetal Alcohol Spectrum Disorder (Accessible at www.nofas-uk.org/OnlineCourse/foetalalcohol.com.htm)

Patient information resources on drinking during pregnancy

- Information for you: Alcohol and pregnancy (RCOG, 2015)[131]
- Information for the public: Routine antenatal care for healthy pregnant women (NICE, 2014)[204]
- Alcofacts – a guide to sensible drinking (Health Challenge Wales, 2007)[205]
- Focus on alcohol – a guide to drinking and health (PHA Northern Ireland, 2011)[206]
- NHS Choices information on alcohol in pregnancy (Accessible at www.nhs.uk)
- NHS Health Scotland internet resource Ready, Steady, Baby (Accessible at www.readysteadybaby.org.uk)

Appendicies

Appendix 1 – Fetal alcohol spectrum disorder – ethics, rights, duties

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Pregnant women frequently go to considerable lengths to promote the wellbeing of the children they wish to have. They will often make changes in their lifestyles to maximise the chances of having a healthy child, and quite naturally seek advice from health professionals to inform those decisions. The stories in this report by those who were harmed by their mother's drinking show that this is not always the case. There are times when some pregnant women act in ways that risk causing harm to the fetus – and to the future person the fetus will become.

When the interests of a pregnant woman and the wellbeing of the fetus diverge, we can be forced to confront complex ethical questions, questions that are subject to deep and at times angry disagreement. They are also multi-dimensional questions. Although they begin in the private sphere with personal decisions about whether to have a child, they cannot necessarily remain there. The interests of the future child will at some point come into view. Society will begin to take an interest, and so apparently private moral questions can become the focus of legal as well as medical attention and, as with this guidance, the target of social policy.

This guide also sets FASD within calls for wider regulatory change to reduce population levels of alcohol consumption. Public health interventions aiming to change individual behaviour can themselves give rise to sharp ethical and political conflicts that demand reflection on the scope and justification of state interventions in the private choices of citizens. Arguably there is a structural tension within liberal states between obligations to promote our welfare and duties to protect our private freedoms.

The BMA is committed to improving individual and public health. Many, if not most of its members have first-hand experience of the devastating impact that excessive alcohol consumption can have, on those who drink, and on those around them. As a medical body, the BMA has a key role to play in providing scientific evidence about the impact of alcohol consumption to inform people's drinking choices. But as a leading medical voice in the UK it also has a role in lobbying government to create the right environment for people to make healthy choices. Questions about how far the choices of adults should be subject to state pressure are political. Personal freedom is important. But freedom is about more than being left alone. It is also about creating the conditions in which freedom can be realised. This is controversial territory. Getting the balance right is not easy. Although the evidence is clear that there is a social gradient in health, messages about positive change have shown themselves vulnerable to media accusations of 'nannying'. At the same time, public health messages that do not resonate with people's lives, and do not speak to them as free individuals, can be ignored.

This section briefly explores some of the ethical issues that arise in this challenging area.

The rights of a pregnant woman

In the UK, the legal position is clear: a fetus does not have legal rights against the woman who carries it.[m] A 2014 case in the Court of Appeal considered whether a child could claim criminal compensation as a result of being born with FASD.[207] The Court held that a fetus did not constitute a person under the relevant statute – the Offences Against the Person Act 1861. It also emphasised that in civil law it is established that pregnant women owe no legal duty of care to the fetus. In the UK, women have rights to make their own decisions during pregnancy and this extends to whether and how much they drink. Legally, a woman's freedom cannot be constrained by reference to the wellbeing of the fetus she carries. We can think of this as an adult woman's right to non-interference and bodily integrity. The

m For an account of the approach of the European Court of Human Rights to abortion, see Vo v France (2005) 40 EHRR 12.

situation differs in some other jurisdictions. In certain American states, pregnant women who seriously threaten the wellbeing of their fetus through drug or alcohol misuse can be incarcerated for the protection of the future child. (It can be helpful to ask whether incarceration would be considered for pregnant women who put their fetus at risk in other ways, by involvement in extreme sports or continuing in high-risk occupations. Is risk itself the morally important issue or is there something particularly problematic about drug and alcohol use?)

Moral duties to the fetus?

The legal position in the UK does not exhaust the ethical issues involved. Although the fetus has no legal rights, and the pregnant woman no legal duties, it does not follow that a pregnant woman owes no duties of any kind to a fetus she wishes to carry to term. These duties may not be enforceable, but it is difficult to imagine a parental relationship devoid of any such duties whatsoever. We tend to think quite naturally that parents ought to look after their children, providing for them in so far as they can, and safeguarding provisions may remove parental rights from parents who neglect or harm their child after birth. It is also entirely coherent to say that women owe these duties to a fetus they wish to carry to term – they ought to care about its welfare. As we have seen, what is at stake is not just an ethical issue, but a political one: how far and with what justification should the state be able to intrude into our private lives?

Weighing maternal and fetal interests

Within the overall legal framework, and the acknowledgement of a woman's right to non-interference, perhaps the most urgent ethical issue we need to confront is how we understand and weight the interests of the pregnant woman and the fetus and how we adjudicate between them. In turn this leads us to ask questions about the moral value of the fetus. Views differ widely. Some argue that the fetus acquires full moral value at conception, others see it growing in moral value during the course of pregnancy, increasing as it grows closer to term. Still others argue that full moral value only arrives with the development of those capacities that constitute human personhood, such as self-consciousness and rationality, capacities which may well develop a considerable time after birth. Connected to this, we will also need to ask whether a fetus can meaningfully be said to have interests, or is it the interests of the future child that should be the focus of attention, interests that it will acquire as it grows? And if our concern is with the future child, does it follow that, somehow retrospectively, we owe the fetus the same regard? All of these questions are subject to significant and ongoing moral disagreement.

Women's rights: culture and history

Discussion of maternal and fetal rights emerges from within, and is influenced by, its social context. There is a strong public interest in ensuring the wellbeing of future children, and, in terms of this report, preventing FASD. Given the harms that heavy maternal drinking can visit upon the future child, questions naturally arise about the proper scope of state intervention. Health professionals have a key role in providing information and support, particularly where women wish to limit their drinking but find it difficult. Beyond the provision of information and relevant health services, calls for a more coercive approach are controversial. We have seen that in the UK women have significant rights over their bodies. Laws can be changed, but any move toward conferring legal rights on fetuses that are enforceable against the pregnant woman would have significant repercussions. It might, for example, undermine existing rights for women in England, Wales and Scotland, to seek an abortion. Also, if more coercive interventions are considered in relation to maternal drinking, perhaps other maternal freedoms should be constrained: should pregnant women be prevented from smoking or even from risky sports? And if women should be prevented from activities that may harm the fetus, should they be under an obligation to take positive steps to promote the wellbeing of the fetus: should their diets, for example, be regulated? When we push the example toward extremes, the underlying issues can become clearer: it could be perceived that fundamental liberties are at stake.

Private choices, public health

Whether we are pregnant or not, as adults the choices we make about how much to drink seem paradigmatically private. Setting addiction aside, how much we drink, like how much we eat, feels like a matter of personal choice. If we take a step back from this individual perspective though and consider people in aggregate, we see that health outcomes are influenced by factors over which we have little or no personal control. Statistically, our background, environment, education and social status affect our health, and these factors are not simply matters of personal choice. Powerful commercial interests also seek to alter our patterns of consumption, and, as this report makes clear, social mores strongly influence individual choice. Although in the UK overall levels of alcohol consumption among women are declining, instances of binge drinking remain persistently high among women of reproductive age. So we need to grasp what can look like a paradox: our choices are to some degree both free and constrained.

Public health interventions – the need for justification

One aspect of this report looks at individual women and their private choices, while another looks out toward the wider social context that shapes behaviour. We have acknowledged the importance of individual freedom in liberal states, specifically the freedom of citizens to shape the course of their own lives. Freedom is complex though. One useful, albeit disputed, way of thinking about freedom is to see it as possessing two aspects or dimensions: 'negative' and 'positive'. Its 'negative' aspect refers to our freedom from interference. With the exception of some seriously mentally-disordered people, we all have the right for example to say no to medical treatment, even if it results in our death. Pregnant women also have a right to refuse medical treatment even where it may be necessary to save the life of their fetus. The law constrains the state, setting limits on its power.

Arguably though, for it to be meaningful, freedom requires more than just a right to non-interference. It also has a 'positive' aspect. Those who promote a 'positive' conception of freedom may be less concerned with the absence of external constraint and more interested in securing the conditions for people to shape their own lives. These conditions will often include a certain minimum level of education and, as far as possible, a reasonable standard of health. And if positive freedoms are linked to certain basic capabilities, the evidence is clear that these are distributed unequally in our society – they have a social gradient. The wellbeing of vulnerable groups, and of those with fewer of the basic capabilities are therefore of particular public health concern.

Where states are held to have a justified responsibility for promoting positive freedom, their scope and powers can be greatly extended. The provision of free education and health services involve taxation, and, in relation to education, significant encroachment into the negative freedoms of children and their parents. Although there is no necessary conflict between negative and positive freedoms, where private choices undermine individual and public health, the state's obligation to promote our negative and positive freedoms – to protect our autonomy and promote our welfare – can come into tension.

Although medicine can provide important scientific data to identify the harms of drinking, getting the appropriate balance between these freedoms is a political issue. We know that excessive drinking can have a catastrophic effect on people's lives, and of the lives of those around them. If we set pregnant women aside for a moment, many people see the consumption of moderate amounts of alcohol as a positive and pleasurable part of their lives and enjoy it without demonstrable harm. Calls to limit access to alcohol in order to address problematic drinking, for example through taxation or minimum unit pricing, must seek a politically justifiable balance between our autonomy and welfare interests.

A stepped approach to public health interventions?

In an influential report on ethical issues in public health, the Nuffield Council on Bioethics proposes an 'intervention ladder'.[208] It seeks to weigh interventions in terms of 'their intrusiveness and likely acceptability.' The report begins with a rich interpretation of the English philosopher John Stuart Mill's harm principle. This states that '...the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.'[209] Drawing on Mill's insights, and adding a communal dimension, the Nuffield sets out a 'revised' liberal framework for public health interventions that balances individual freedoms with the promotion and protection of important social goals.

According to the Nuffield Council, these interventions should seek to minimise health risks that people present to each other while paying particular attention to those whose autonomy may be compromised or developing such as children and vulnerable adults. The justified goals of public health will therefore include:

- ensuring environmental conditions are conducive to good health such as the provision of clean water, safe food and decent housing
- the provision of information and advice to inform health-promoting decisions
- the provision of health services, including services to help people struggling with addictions or other unhealthy behaviours
- the delivery of appropriate medical services
- the tackling of unfair health inequalities.

As a revised liberal framework it argues that there should be some liberty-protecting constraints on public health interventions. A liberal state will not coerce adults into healthy lives. It will minimise interventions introduced without the consent of those affected by them, and avoid interventions that are unduly intrusive or in conflict with important personal values.

From out of this framework rises the 'intervention ladder'. The bottom rung – no intervention – maximally protects individual freedom. At the top rung the state eliminates individual choice altogether. The higher up the ladder the intervention falls, the greater must be the justification for restricting freedom.

Conclusion

As this guide makes clear, heavy maternal drinking can cause serious harm to the fetus and to the future child. Health professionals have a vital role to play in the identification of problem drinking and the provision of supportive services to help those pregnant women who struggle to control their drinking. In this section we have drawn out some of the ethical issues that arise where there may be conflicts between the interests of the mother and the fetus. Guidance in this report is also set within wider calls for population-level change in drinking habits. Public health interventions themselves give rise to ethical and political questions concerning the proper relationship between the state and private individuals. The Nuffield Council's intervention ladder is one influential recent response to these questions. Not everyone will agree with the Nuffield. Libertarians will seek greater constraints on state interventions; communitarians may argue that some more coercive interventions are justifiable. What it does make clear is that when it comes to FASD, and to state intervention in individual lives, particularly for our own benefit, we are in contested territory.

Appendix 2 – Different criteria for FASD diagnosis

IoM criteria for FASD diagnosis

I. FAS with Confirmed Maternal Alcohol Exposure (requires all features A–D)

A Confirmed maternal alcohol exposure

B Evidence of a characteristic pattern of minor facial anomalies, including ≥2 of the following
1. Short palpebral fissures (≤10th percentile)
2. Thin vermilion border of the upper lip (score 4 or 5 with the lip/philtrum guide)
3. Smooth philtrum (score 4 or 5 with the lip/philtrum guide)

C Evidence of prenatal and/or postnatal growth retardation
1. Height or weight ≤10th percentile, corrected for racial norms, if possible

D Evidence of deficient brain growth or abnormal morphogenesis, including ≥1 of the following
1. Structural brain abnormalities
2. Head circumference ≤10th percentile

II. FAS without Confirmed Maternal Alcohol Exposure

IB, IC, and ID, as above

III. Partial FAS With Confirmed Maternal Alcohol Exposure (requires all features, A–C)

A Confirmed maternal alcohol exposure

B Evidence of a characteristic pattern of minor facial anomalies, including ≥2 of the following
1. Short palpebral fissures (≤10th percentile)
2. Thin vermilion border of the upper lip (score 4 or 5 with the lip/philtrum guide)
3. Smooth philtrum (score 4 or 5 with the lip/philtrum guide)

C One of the following other characteristics
1. Evidence of prenatal and/or postnatal growth retardation
   a) Height or weight ≤10th percentile corrected for racial norms, if possible
2. Evidence of deficient brain growth or abnormal morphogenesis, including ≥1 of the following
   a) Structural brain abnormalities
   b) Head circumference ≤10th percentile
3. Evidence of a complex pattern of behavioural or cognitive abnormalities inconsistent with developmental level that cannot be explained by genetic predisposition, family background, or environment alone
   a) This pattern includes marked impairment in the performance of complex tasks (complex problem solving, planning, judgment, abstraction, metacognition, and arithmetic tasks); higher-level receptive and expressive language deficits; and disordered behaviour (difficulties in personal manner, emotional lability, motor dysfunction, poor academic performance, and deficient social interaction)

IV. Partial FAS without Confirmed Maternal Alcohol Exposure

IIIB and IIIC, as above

V. ARBD (requires all features, A–C)

A Confirmed maternal alcohol exposure

B Evidence of a characteristic pattern of minor facial anomalies, including ≥2 of the following
   1. Short palpebral fissures (≤10th percentile)
   2. Thin vermilion border of the upper lip (score 4 or 5 with the lip/philtrum guide)
   3. Smooth philtrum (score 4 or 5 with the lip/philtrum guide)

C Congenital structural defects in ≥1 of the following categories, including malformations and dysplasias (if the patient displays minor anomalies only, ≥2 must be present): cardiac: atrial septal defects, aberrant great vessels, ventricular septal defects, conotruncal heart defects; skeletal: radioulnar synostosis, vertebral segmentation defects, large joint contractures, scoliosis; renal: aplastic/hypoplastic/dysplastic kidneys, 'horseshoe' kidneys/ureteral duplications; eyes: strabismus, ptosis, retinal vascular anomalies, optic nerve hypoplasia; ears: conductive hearing loss, neurosensory hearing loss; minor anomalies: hypoplastic nails, short fifth digits, clinodactyly of fifth fingers, pectus carinatum/excavatum, camptodactyly, 'hockey stick' palmar creases, refractive errors, 'railroad track' ears

VI. ARND (requires both A and B)

A Confirmed maternal alcohol exposure

B At least one of the following
   1. Evidence of deficient brain growth or abnormal morphogenesis, including ≥1 of the following
      a) Structural brain abnormalities
      b) Head circumference ≤10th percentile
   2. Evidence of a complex pattern of behavioural or cognitive abnormalities inconsistent with developmental level that cannot be explained by genetic predisposition, family background, or environment alone.
      a) This pattern includes marked impairment in the performance of complex tasks (complex problem solving, planning, judgment, abstraction, metacognition, and arithmetic tasks); higher-level receptive and expressive language deficits; and disordered behaviour(difficulties in personal manner, emotional lability, motor dysfunction, poor academic performance, and deficient social interaction)

Source: Hoyme HU, May PA, Kalberg WO et al (2005) A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 Institute of Medicine Criteria. Pediatrics **115**: 39-47.

CDC guidelines and criteria for FAS/FAE (fetal alcohol effect)

Facial dysmorphia

Based on racial norms, individual exhibits all three characteristic facial features:

- Smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Thin vermillion border (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile)

Growth problems

Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time (adjusted for age, sex, gestational age, and race or ethnicity)

Central Nervous System Abnormalities

1. **Structural**
   - Head circumference (OFC) at or below the 10th percentile adjusted for age and sex
   - Clinically significant brain abnormalities observable through imaging

2. **Neurological**
   Neurological problems not due to a postnatal insult or fever, or other soft neurological signs outside normal limits

3. **Functional**
   Performance substantially below that expected for an individual's age, schooling, or circumstances, as evidenced by:
   - global cognitive or intellectual deficits representing multiple domains of deficit (or significant developmental delay in younger children) with performance below the 3rd percentile (2 standard deviations below the mean for standardized testing), or
   - functional deficits below the 16th percentile (1 standard deviation below the mean for standardized testing) in at least three of the following domains:
     a) cognitive or developmental deficits or discrepancies
     b) executive functioning deficits
     c) motor functioning delays
     d) problems with attention or hyperactivity
     e) social skills
     f) other, such as sensory problems, pragmatic language problems, memory deficits, etc

Maternal Alcohol Exposure

1. Confirmed prenatal alcohol exposure
2. Unknown prenatal alcohol exposure

Criteria for FAS Diagnosis

Requires all three of the following findings.

1. Documentation of all three facial abnormalities (smooth philtrum, thin vermillion border, and small palpebral fissures);
2. Documentation of growth deficits
3. Documentation of CNS abnormality

Source: Bertrand J, Floyd RL, Weber MK, O'Connor M et al. (2005) *National Task Force on FAS/FAE: Guidelines for referral and diagnosis*. Atlanta: CDC.

4-Digit Diagnostic Code

The 4 digits of the diagnostic code reflect the magnitude of expression of the 4-key diagnostic features of FASD, in the following order: (1) growth deficiency, (2) FAS facial phenotype, (3) CNS abnormalities, and (4) prenatal alcohol exposure. There are 256 possible 4-digit diagnostic codes, ranging from 1111 to 4444. Each of the 4-digit diagnostic codes falls into one of 22 unique clinical diagnostic categories. Eight of the 22 diagnostic categories fall broadly under the designation of FASD. The 4-digit code (3444) that is inserted in the grid is one of the codes that meet the diagnostic criteria for FAS.

			3	4	4	4	
Severe	Severe	Definite (4)		X	X	X	(4) High risk
Moderate	Moderate	Probable (3)	X				(3) Some risk
Mild	Mild	Possible (2)					(2) Unknown
None	None	Unlikely (1)					(1) No risk
			Growth	**Face**	**CNS**	**Alcohol**	
Growth deficiency	**FAS Facial features**	**CNS damage**					**Prenatal alcohol**

Source: Astley SJ (2006) Comparison of the 4-Digit Code and the Hoyme Diagnostic Guidelines for Fetal Alcohol Spectrum Disorders. Pediatrics **118**: 1532-45.

Canadian FASD guidelines

The criteria for the diagnosis of fetal alcohol syndrome, after excluding other diagnoses, are:

A. Evidence of prenatal or postnatal growth impairment, as in at least one the following:
   a. Birth weight or birth length at or below the 10th percentile for gestational age.
   b. Height or weight at or below the 10th percentile for age.
   c. Disproportionately low weight-to-height ratio (= 10th percentile).
B. Simultaneous presentation of all three of the following facial anomalies at any age:
   a. Short palpebral fissure length (2 or more standard deviations below the mean).
   b. Smooth or flattened philtrum (rank 4 or 5 on the lip-philtrum guide).
   c. Thin upper lip (rank 4 or 5 on the lip-philtrum guide).
C. Evidence of impairment in three or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
D. Confirmed (or unconfirmed) maternal alcohol exposure.

The diagnostic criteria for partial fetal alcohol syndrome, after excluding other diagnoses, are:

A. Simultaneous presentation of two of the following facial anomalies at any age:
   a. Short palpebral fissure length (2 or more standard deviations below the mean).
   b. Smooth or flattened philtrum (rank 4 or 5 on the lip-philtrum guide).
   c. Thin upper lip (rank 4 or 5 on the lip-philtrum guide).
B. Evidence of impairment in three or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
C. Confirmed maternal alcohol exposure.

The diagnostic criteria for alcohol-related neurodevelopmental disorder, after excluding other diagnoses, are:

A. Evidence of impairment in 3 or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
B. Confirmed maternal alcohol exposure.

The term alcohol-related birth defects (ARBD) should not be used as an umbrella or diagnostic term, for the spectrum of alcohol effects. ARBD constitutes a list of congenital anomalies, including malformations and dysplasias and should be used with caution.

Source: Chudley AE, Conry J, Cook JL et al (2005) Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal* **172:**s1–s21.

Diagnostic and Statistical Manual of Mental Disorders (fifth edition DSM-5) – Proposed criteria for ND-PAE (neurodevelopmental disorder associated with prenatal alcohol exposure)

A. Exposed to alcohol at any time during gestation, including prior to pregnancy recognition, and the exposure level was more than minimal (ie more than 13 drinks in any one month, with no more than two drinks on any drinking occasion). Confirmation of gestational exposure to alcohol may be obtained from any of the following sources: maternal self report of alcohol use in pregnancy, collateral reports, or medical or other records.

B. Impaired neurocognitive functioning as manifested by one or more of the following:
   1. Impairment in global intellect
   2. Impairment in executive functioning
   3. Impairment in learning
   4. Memory impairment
   5. Impairment in visual-spatial reasoning

C. Impaired self-regulation as manifested by one or more of the following:
   1. Mood or behaviour
   2. Attention
   3. Impulse control

D. Impairments in adaptive functioning in two or more of the following, including at least either (1) or (2):
   1. Language
   2. Social communication and interaction
   3. Daily living skills
   4. Motor skills

E. The onset of the disturbance (symptoms in Criteria B, C, and D) is before 18 years of age.

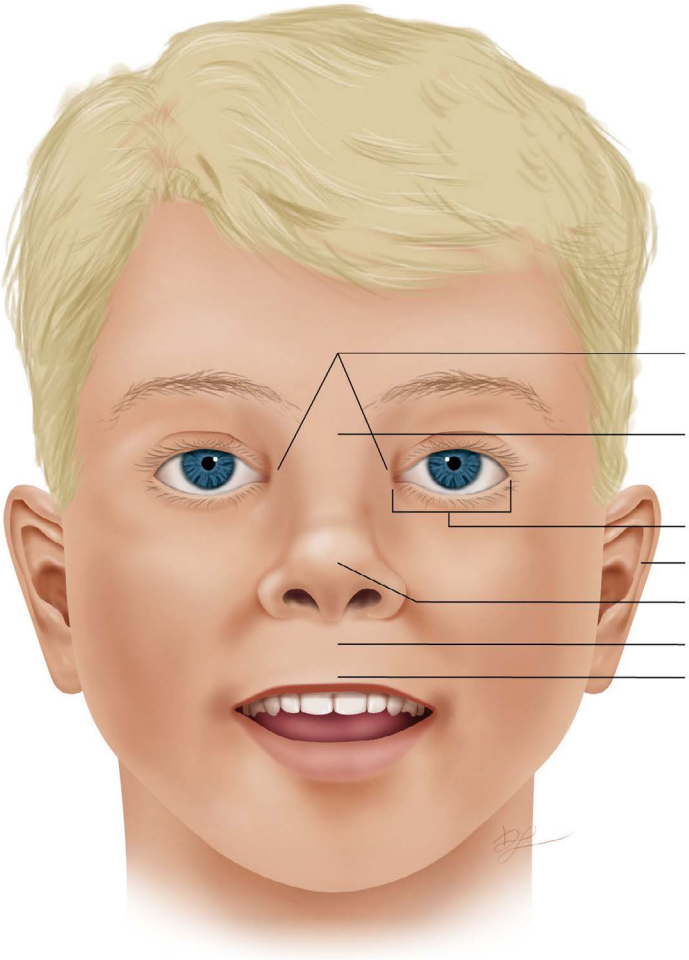
F. The disturbance causes clinically significant distress or impairment in social, academic, occupational, or other important areas of functioning.

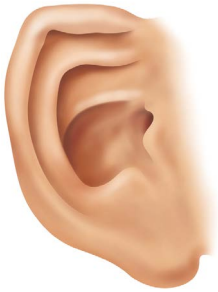
G. The disturbance is not better explained by the direct physiological effects associated with postnatal use of a substance (eg, medication, alcohol or other drugs), another medical condition (eg, traumatic brain injury, delirium, dementia), another known teratogen (eg, Fetal Hydantoin syndrome), a genetic condition (eg, Williams syndrome, Down syndrome, Cornelia de Lange syndrome), or environmental neglect.

Sources: American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5).* Arlington: American Psychiatric Association. Nofas.org

Appendix 3 – Characteristics associated with FASD

Craniofacial features associated with fetal alcohol syndrome





Characteristic features of an ear of a child with fetal alcohol spectrum disorders. Note the underdeveloped upper part of the ear parallel to the ear crease below ("railroad track" appearance).

Characteristic features of a hand of a child with fetal alcohol spectrum disorders. Note the curved fifth finger (clinodactyly) and the upper palmar crease that widens and ends between the second and third fingers ("hockey stick" crease).

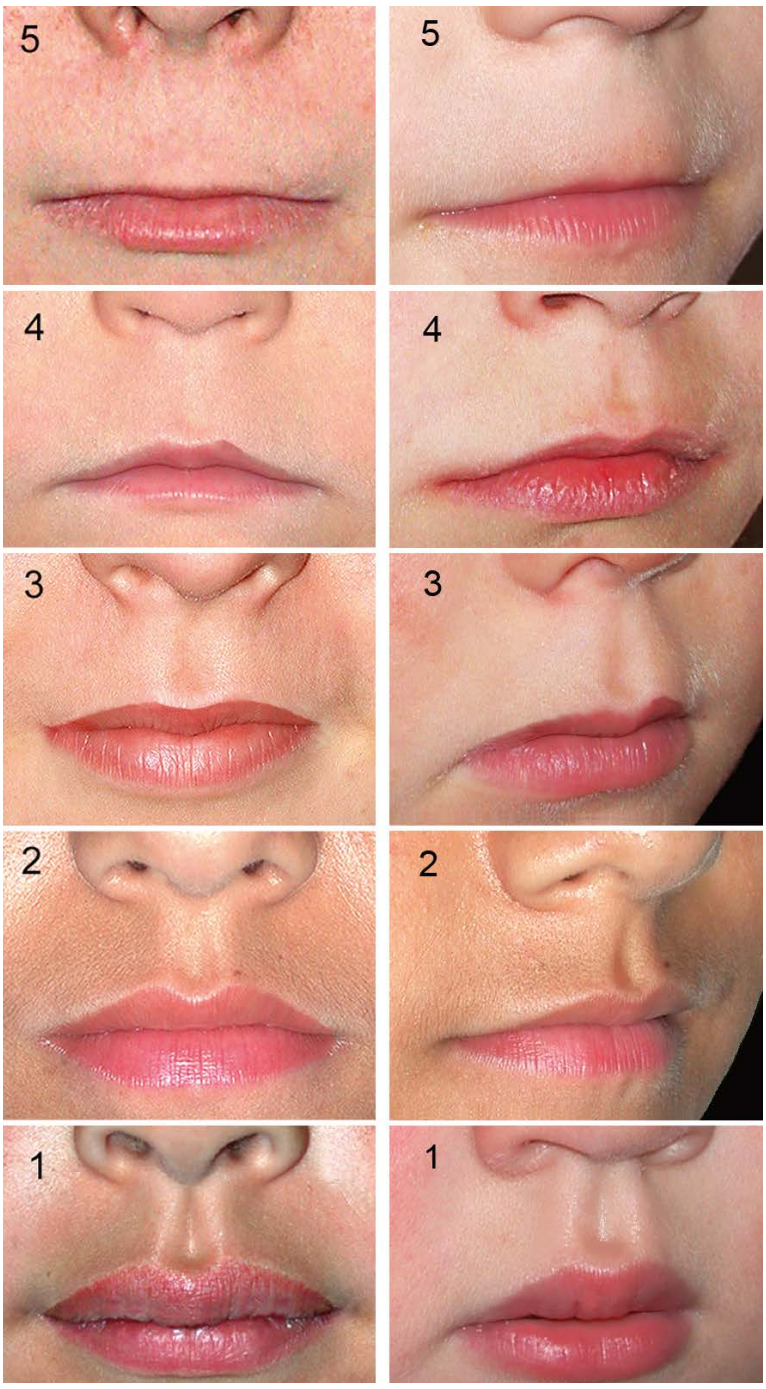
Images courtesy of Darryl Leja, National Human Genome Research Institute, National Institutes of Health, Bethesda, MD.

Source: Wattendorf DJ, Usaf MC & Muenke M (2005) *Fetal Alcohol Spectrum Disorders*. National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland. American Family Physician **72** (2)

Lip-Philtrum Guides 1 (A) and 2 (B) are used to rank upper lip thinness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guides reflect the full range of lip thickness and philtrum depth with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 1 is used for Caucasians and all other races with lips like Caucasians. Guide 2 is used for African Americans and all other races with lips as full as African Americans. Copyright 2015, Susan Astley PhD, University of Washington

FASD 4-Digit Diagnostic Code

A



Lip-Philtrum Guide 1 **Philtrum Guide**

For use as a digital image on a smartphone or tablet. Printing invalidates Guide.

Squares ensures length by width ratio of image is correct.

Lip-Philtrum Guides 1 (A) and 2 (B) are used to rank upper lip thinness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guides reflect the full range of lip thickness and philtrum depth with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 1 is used for Caucasians and all other races with lips like Caucasians. Guide 2 is used for African Americans and all other races with lips as full as African Americans. Copyright 2015, Susan Astley PhD, University of Washington

FASD 4-Digit Diagnostic Code

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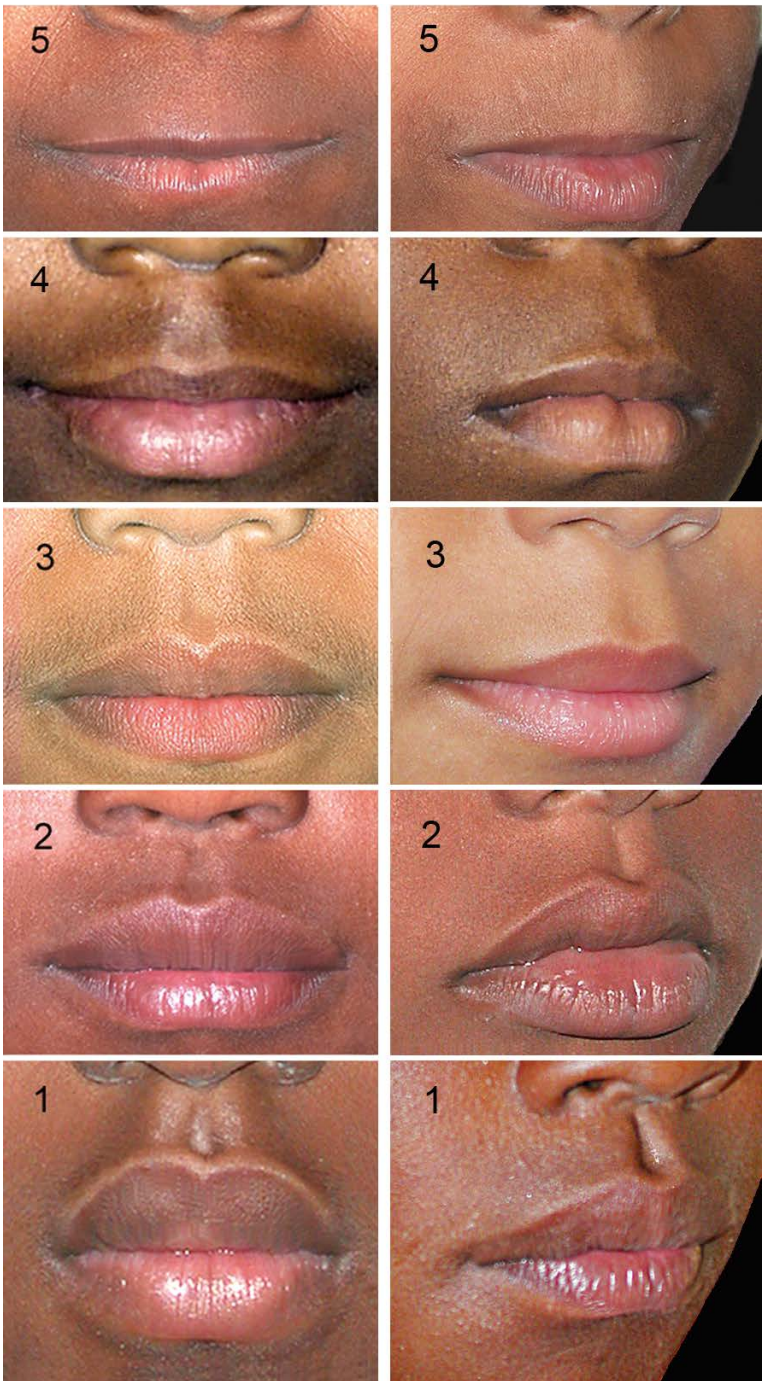
B



Lip-Philtrum Guide 2 **Philtrum Guide**

For use as a digital image on a smartphone or tablet. Printing invalidates Guide.

Squares ensures length by width ratio of image is correct.

Appendix 4 – Maternal alcohol consumption and fetal behaviour

The effects of alcohol consumption during pregnancy have been extensively studied with respect to the individual after birth. Very few studies have focused on the adverse effects on the fetus. It is widely accepted that consumption of alcohol by women during their pregnancy may result in adverse effects on the individual's health and wellbeing after birth.[67] There is little dispute that these effects result from exposure to alcohol while in the womb and that the neurobehavioural effects result from some influence of alcohol on the development and functioning of the individual's CNS. It is a matter of debate how much alcohol is required before the effects of exposure are found. Recent advances in studying the function of the fetus's CNS through observation of its behaviour may enable an assessment to be made of the levels of alcohol that adversely affect development.

Fetal behaviour can be defined as any observable action or reaction (to an external stimulus) by the fetus.[210] The behaviour may be spontaneous, that is endogenously generated by the fetus itself, or elicited, that is occurs in response to an external stimulus.[n] Observing fetal behaviour using real-time, four-dimensional ultrasound offers the opportunity to assess the influence of exposure to alcohol on the functioning of the fetus's brain and CNS.[210,211,212]

Case studies have reported that chronic and acute consumption of alcohol at high levels disrupts the normal behaviour patterns exhibited by the fetus.[213,214,215] There have been few studies examining the behaviour of the fetus following acute maternal consumption of low levels of alcohol. It has been consistently reported that consumption of alcohol exerts an immediate effect on behaviour through a rapid decrease in fetal breathing movements, lasting for two hours or more.[90,91,92,93] With the more alcohol consumed the longer the period that breathing movements are were decreased.[90,91,92,93] One study examined this in more detail and observed reduced fetal eye movements, and as a consequence the behavioural state organisation of the fetus was disrupted.[93] Together these studies demonstrate that acute exposure to even small amounts of alcohol (eg one to two units) may rapidly suppresses the behaviour of the fetus and influence the functioning of the fetus's nervous system in the short term. There can be no doubt of the potential for alcohol to influence the functioning of the fetus's nervous system. The question remains as to what levels and duration of consumption are required before a permanent effect on the nervous system occurs.

The chronic (permanent) effects of alcohol on fetal behaviour have been demonstrated in a series of studies of pregnant women drinking low-to-medium levels of alcohol but who had no alcohol in their body at the time of observation (ie the effects did not result from acute alcohol exposure).[94, 95] These studies observed spontaneous and elicited fetal startle responses.[o] An initial study found that at 27 weeks of gestation fetuses of mothers who drank alcohol exhibited a greater number of spontaneous startles but were less likely to exhibit a startle to an external stimulus than were fetuses of mothers who did not drink alcohol.[94] The mean number of units of alcohol consumed by women in the study was 2.43+/- 1.37 per week, and there was no correlation between the amount drunk and effects on the fetus.[94] The consumption of alcohol has also been associated with a delayed emergence of the elicited fetal startle response.[95,216] A separate study found that whilst exposure to alcohol increased the incidence of startle behaviour across gestation, it appeared to delay the decrease in the incidence of startles observed with development.[95]

n The first spontaneous movements of the fetus are observed around 7-8 weeks of gestation and are slow movements that appear to begin in the back or spine and may result in the passive displacement of the arms and legs. A wide range of movements subsequently develop and by about 20 weeks gestation the fetus exhibits most of the movements that it will produce during its time *in utero*, and exhibits motor patterns similar to those observed in pre-term and term infants. In terms of elicited movements, the fetus first responds to auditory stimuli at around 24-26 weeks of gestation and to visual stimuli at 26-28 weeks gestation.

o Fetal startle responses appear as rapid movements of the body lasting about one second that can occur spontaneously or in response to a stimulus. Spontaneous and elicited startles are influenced by the development of the nervous system. Spontaneous fetal startles emerge at approximately eight weeks of pregnancy and decrease in incidence after approximately nine weeks of gestation. Elicited startle responses occur later in pregnancy (from approximately 24 to 26 weeks gestation) and become more developed (ie occur more rapidly and directly following presentation of a stimulus) as the nervous system develops.

Mothers who consumed alcohol in this study consumed an average of 4.2 +/-1.9 units of alcohol per week. As development progressed, those fetuses exposed to alcohol caught up with the behaviour of fetuses not exposed to alcohol.[95] At 35 weeks gestation, however, even though there was a significant catch up, the number of startles exhibited was still significantly different; with fetuses of mothers exposed to alcohol exhibiting more spontaneous startles than fetuses of mothers not exposed to alcohol.[95] These findings indicate that chronic consumption at low levels of exposure (ie two to five units per week) may delay the development of the fetus's nervous system which may result in a permanent effect.

The observations have a number of implications for determining the best advice to be given to women during their pregnancy. Studies of acute exposure indicate that the fetus is affected by even one glass of alcohol in the short term. Thus it is not possible to say that one glass of alcohol does not affect the fetus. Moreover, there appears to be a dose dependent effect in that any effect on behaviour persists for longer at higher doses of alcohol exposure. How this relates to the neurobehavioural effects observed after birth is unknown. Other studies examining chronic effects of low dose alcohol exposure (three to five drinks per week) indicate that this does induce a delay in the fetus's behavioural development.

Appendix 5 – UK guidelines on alcohol consumption during pregnancy

Guidance source	Recommendation
UK chief medical officers (CMOs)	In January 2016 the UK chief medical officers published proposed new guidance on alcohol consumption during pregnancy, stating that: – if you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum. – drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk. The guidance on alcohol consumption during pregnancy that existed from UK chief medical officers, prior to January 2016 is as follows. Chief medical officer for England: 'Women who are pregnant or trying to conceive should avoid alcohol altogether. However, if they do choose to drink, to minimise the risk to the baby, we recommend they should not drink more than 1-2 units once or twice a week and should not get drunk.' Scottish chief medical officer: 'It is best to avoid alcohol completely during pregnancy as any alcohol drunk while pregnant will reach the baby and may cause harm. Women who are trying to conceive should also avoid drinking alcohol. There is no 'safe' time for drinking alcohol during pregnancy and no 'safe' amount.' https://www.gov.uk/government/consultations/health-risks-from-alcohol-new-guidelines http://www.nhs.uk/chq/Pages/2270.aspx?CategoryID=54#close http://www.scotland.gov.uk/Publications/2013/04/2305/4

Guidance source	Recommendation
National Institute for Health and institute (NICE) Antenatal care (March, 2008, updated 2014)	Pregnant women and women planning a pregnancy should be advised to avoid drinking alcohol in the first 3 months of pregnancy if possible because it may be associated with an increased risk of miscarriage. If women choose to drink alcohol during pregnancy they should be advised to drink no more than 1 to 2 UK units once or twice a week (1 unit equals half a pint of ordinary strength lager or beer, or one shot [25 ml] of spirits. One small [125 ml] glass of wine is equal to 1.5 UK units). Although there is uncertainty regarding a safe level of alcohol consumption in pregnancy, at this low level there is no evidence of harm to the unborn baby. Women should be informed that getting drunk or binge drinking during pregnancy (defined as more than 5 standard drinks or 7.5 UK units on a single occasion) may be harmful to the unborn baby. http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf
Department of Health, Social Services and Public Safety (Northern Ireland) Alcohol and Drug Misuse	The best advice is to avoid drinking alcohol when you are pregnant or trying to conceive. If you do decide to drink, then make sure it is no more than one or two units just once or twice a week, and don't get drunk. If you stick to this, the evidence suggests it's highly unlikely you'll harm your baby. http://www.dhsspsni.gov.uk/index/phealth/php/alcohol_and_drug_misuse.htm
Royal College of Obstetricians and Gynaecologists (RCOG) Alcohol and pregnancy (February 2015)	There is no proven safe amount of alcohol that you can drink during pregnancy. It is also often difficult to work out just how much you are drinking, especially if you have a drink at home. The only way to be certain that your baby is not harmed by alcohol is not to drink at all during pregnancy or while breastfeeding. It is recommended that you do not drink alcohol during the first three months of pregnancy. Drinking small amounts of alcohol after this time does not appear to be harmful for the unborn baby, but you should not: – drink more than one or two units, and then not more than once or twice per week – binge drink (which for a woman is when she has six units or more of alcohol on any one occasion). To make sure that you stay within the recommended amount, you need to check how strong your drink is, how large your glass is and how full your glass is. https://www.rcog.org.uk/en/patients/patient-leaflets/alcohol-and-pregnancy/

Appendix 6 – T-ACE, TWEAK and AUDIT-C alcohol screening questionnaires

T-ACE

The T-ACE alcohol screening questionnaire consists of four questions that take less than a minute to answer, including:

1. **Tolerance** – how many drinks does it take to make you feel high?
2. **Annoyance** – have people annoyed you by criticising your drinking?
3. **Cut down** – have you ever felt you ought to cut down on your drinking?
4. **Eye-opener** – have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?

A single point is given to an affirmative answer to the A, C and E questions, and two points are given when a pregnant women indicates a tolerance of more than two drinks to feel high. A total score of two or more on the T-ACE test is suggestive of harmful drinking patterns during pregnancy.

Source: Sokol RJ, Martier SS & Ager JW (1989) The T-ACE questions: practical prenatal detection of risk-drinking. American Journal of Obstetrics and Gynecology **160**: 863–8.

TWEAK

There are two versions of the TWEAK screening questionnaire: one that is recommended for populations with high levels of binge drinking and one that is recommended for populations with low levels of binge drinking. Please note that as these questionnaires have been developed in the USA, the drinking levels stated refer to the US levels.

The TWEAK alcohol screening questionnaire for populations with high levels of binge drinking consists of five questions including:

1. **Tolerance (T)** – how many drinks does it take before the alcohol makes you fall asleep or pass out?

   Record number of drinks (a positive score is six or more drinks)

   Or

   If you never drink until you pass out, what is the largest number of drinks that you have?

   Record number of drinks (a positive score is six or more drinks)
2. **Worried (W)** – have your friends or relatives worried or complained about your drinking in the past year?
3. **Eye opener (E)** – do you sometimes take a drink in the morning when you first get up?
4. **Amnesia (A)** – are there times when you drink and you can't remember what you said or did?
5. **Cut down (K)** – do you sometimes feel the need to cut down on your drinking?

The TWEAK alcohol screening questionnaire for populations with low levels of binge drinking consists of five questions including:

1. **Tolerance (T**) – how many drinks does it take before you begin to feel the first effects of alcohol?

   Record number of drinks (a positive score is three or more drinks)

2. **Worried (W)** – have your friends or relatives worried or complained about your drinking in the past year?
3. **Eye opener (E)** – do you sometimes take a drink in the morning when you first get up?
4. **Amnesia (A)** – are there times when you drink and you can't remember what you said or did?
5. **Cut down (K)** – do you sometimes feel the need to cut down on your drinking?

For each version, a positive response to question T or W yields two points each, and an affirmative reply to question E, A or K scores one point each. A total score of two or more points on the TWEAK test is suggestive of harmful drinking patterns during pregnancy.

Source: Chan AWK, Pristach EA, Welte JW et al (1993) Use of the TWEAK test in screening for alcoholism/heavy drinking in three populations. Alcoholism: Clinical and Experimental Research **17**: 1188-92.

AUDIT-C

The AUDIT-C is a three-question alcohol screen that can help identify individuals who are hazardous drinkers. It includes the following questions:

1. **How often do you have a drink containing alcohol?**
   Never (0 points), Monthly or less (1 point), Two to four times a month (2 points)
   Two to three times a week (3 points), Four or more times a week (4 points)

2. **How many drinks containing alcohol do you have on a typical day when you are drinking?**
   1 or 2 (0 points), 3 or 4 (1 point), 5 or 6 (2 points), 7 to 9 (3 points), 10 or more (4 points)

3. **How often do you have six or more drinks on one occasion?**
   Never (0 points), Less than monthly (1 point), Monthly (2 points), Weekly (3 points), Daily or almost daily (4 points)

Taking a sum of the responses to these three questions results in possible AUDIT-C scores of 0–12 points. It is recommended that screening thresholds should be set at ≥3 points for women.

Source: Frank D, DeBenedetti AF, Volk RJ et al (2008) Effectiveness of the AUDIT-C as a screening test for alcohol misuse in three race/ethnic Groups. *Journal of General Internal Medicine* **23**(6): 781-787

Appendix 7 – Indicated prevention interventions in the USA

A number of studies have assessed approaches aimed at preventing PAE in high-risk women. One of these approaches was the 'Protecting the next pregnancy' project. This project targets women who drank at risk levels during a previous pregnancy, and provides them with intensive brief intervention following the birth of a child affected by PAE. In comparison to a control group, the use of intensive brief interventions was found to reduce alcohol consumption during further pregnancies and subsequently resulted in improved birth outcomes.[182] A second approach, Project TrEAT (Trial for Early Alcohol Treatment), provided brief interventions for women between the ages of 18 and 40 who were identified as problem drinkers. Compared to a control group, women who received brief interventions were found to have reduced their mean alcohol intake and level of binge drinking, and to have reduced alcohol consumption during subsequent pregnancies.[217]

Appendix 8 – Timeline of aspects of management from preconception to adulthood

	Time period	Pre conception
Actions to take	**1** Public education	**1** Monitoring of pregnancy
	2 Pre conception advice	**2** Ongoing advice
		3 Information documentation
		4 Correspondence with colleagues
Responsible practitioners	**1** Government/FAS	**1** GP
	2 GP	**2** Midwife
	3 Addiction psychiatrist	**3** Obstetrician
		4 Addiction psychiatrist

Source: Mukherjee RAS, Hollns S & Turk J (2006) Fetal alcohol spectrum disorder: an overview. Journal of the Royal Society of Medicine **99**: 298-302.

During pregnancy	Childhood 0-18	Adult 18+
1 Early recognition	**1** Diagnosis	
2 Diagnosis	**2** Psychometric assessment	Psychometric, physical investigations and other
3 Psychometric assessment	**3** Physical investigation if not recommended tests	
4 Investigation of background and history from/about birth mother if possible	**4** Educational statement previously undertaken (if required)	
5 Ongoing support as needed	**5** Education of others as to level of function	
6 Physical investigations	**6** Ongoing support	**1** IQ eg WISC/WAIS/NART
7 Behavioural management eg ADHD symptoms	**7** Social	**2** Executive function, eg Delis Kaplan test
8 Further prevention	**8** Financial	**3** Communication assessment
	9 Educational	**4** Brain imaging for microcephaly below 3rd percentile, midline abnormalities and from areas of deceased attenuation
	10 Employment	**5** Physical examination for cardiac, renal and oro-buccal pathology
	11 Management of secondary disabilities	
1 GP	GP specialists	
2 Health visitor	Clinical genetics	
3 Hospital paediatrician	FAS specialist	
4 Community paediatrician	Neurology	
5 Child psychiatrist/team	Public health	
6 FAS specialist	Community mental health teams	
7 Clinical geneticist	General psychiatry	
8 Addiction psychiatrist	Learning disability psychiatry	
9 Neurology	Addiction psychiatry	
10 Public health	Forensic psychiatry	
11 Education services	Psychology	
	Speech and language therapist	
	Social Services Government	

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