Consensus Statement Regarding the Recognition and Diagnosis of Foetal Alcohol Spectrum Disorders Across the Lifespan in the UK: Development of Proposed UK Clinical Pathways

Report on the Findings from the first National Medical and Healthcare Professionals Conference held on the 12th and 13th October 2011

Surrey and Borders Partnership NHS
NHS Foundation Trust

Cambridgeshire and Peterborough NHS
NHS Foundation Trust

Understanding children, young people and families

The Tavistock and Portman NHS
NHS Foundation Trust

East and North Hertfordshire NHS
NHS Trust

Foreword

The FASD Trust is pleased to present the following Consensus Statement as part of its ongoing commitment to raising awareness about the challenges confronting the prevention, diagnosis and management of FASD in the UK. The Medical & Healthcare Professionals Forum arising from the first conference in October 2011 has enabled The FASD Trust to further its charitable aims in progressing towards a coordinated medical network able to confront one of the most pressing healthcare issues in the UK today.

Our sincerest thanks go to everyone who contributed to the compilation of this document and it is hoped that these efforts will be rewarded through raising the profile of FASD in the UK.

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Contents

Summary of the document purpose and aims

The document below is a statement and record of the first national conference of the UK Medical and Healthcare Professionals Forum. It was conceived by members of the organising committee to help establish the clinical picture for Foetal Alcohol Spectrum Disorders (FASD) referrals and care in the UK, as well as to train professionals to improve practice.

In the production of this Consensus Statement, rather than beginning with the aim of trying to redefine what had already been extensively established internationally, a meeting was designed to help develop a clinical process in the UK for FASD. There appeared, from the clinical experience of those working in the field prior to this meeting, a lack of established structure to the process of recording information, referral for support and also knowledge about the issues that required exploration.

The primary purpose, and the main outcome of this meeting, was to define such a process. It was hoped that this would be taken as a model for service delivery and development in the UK. It was considered, however, that this may well also be a process that would lend itself internationally to a model of good integrated care.

The main body of the document below presents a summary of the session and the outcomes established. The later appendices are designed to offer clinicians both a verbatim recording of the groups, in addition to offering some guidance for work in this field. It will present recommendations about methods and tools to be used within the pathways. It must be noted that those aspects were not necessarily the main focus of the session on this occasion. Further work will be needed to establish the evidence for specific interventions at later meetings; they are included here as an initial guide to support clinicians.

Part 1:

Brief Background to FASD
and
Purpose of Consensus Statement

What are Foetal Alcohol Spectrum Disorders?

Foetal Alcohol Spectrum Disorders (FASD) represent a range of conditions that are caused by exposure of a developing foetus to alcohol (1-4). A range of conditions are seen within the FASD diagnostic definitions. These range from the most recognised of the group, Foetal Alcohol Syndrome (FAS). FAS is defined by a triad of facial features (short palpebral fissures, elongated and flattened philtrum and a thin upper lip vermillion), pre and post-natal growth deficits (below the 10^{th} percentile) and neuro-cognitive deficits deriving from a history of alcohol consumption during pregnancy. These are sometimes recoded as dysmorphic FASD. The range of problems extends to non-dysmorphic groups where problems are confined to behaviour and the brain with no obvious external physical signs (Alcohol Related Neurodevelopmental Disorders). This group represents the majority of cases but is also the group that is often the most complex to diagnose. Of these diagnostic definitions only FAS, where all the dysmorphic features, growth parameters and characteristic cognitive profiles are clear, can diagnosis without a confirmed history of alcohol consumption be made. (3;5-7).

FASD are caused by the teratogenic effects of alcohol (4;8). A teratogen is defined as a compound that causes damage to a developing embryo or foetus. Numerous researchers have spent many years highlighting the effects of prenatal alcohol exposure on the foetus. They have shown that not only is there a direct effect of the alcohol on the development of organ systems in the foetus, but that also the timing of the exposure has an impact on the development of facial features and observed outcomes (8;9). The implication here is that intermittent exposure, as seen for example with binge drinking, may not affect features such as the face. This has a short risk exposure period, but prenatal exposure may well affect the brain for a longer period as it has a longer risk exposure period (3;4;10;11).

How common is FASD and is it something that professionals should be more aware of?

The prevalence of FASD in the UK has yet to be established. International studies in different countries have suggested varying rates. For example, in high risk populations such as that found in the Western Cape of South Africa, rates as high as 89 per 1000 were seen. Studies in Europe and high income economies show different rates. For example, one conducted in Italy recorded rates of 35 per 1000. A review of reported rates of FASD in England was conducted by evaluating trends in health episode statistics. This showed an increasing trend in diagnosis over a six year period from 2002 to 2008. Rates were shown to rise by 41% over that time period. Despite this trend, the authors considered that the figures were a potential underestimate and that only through better recognition and understanding would this situation improve (12).

What difficulties are there in the recognition of FASD?

As highlighted, the timing of the alcohol exposure will affect the dysmorphic features that are evident. This is also the case for the brain. Whilst the brain develops through most of the pregnancy, different parts develop at different points during the pregnancy. This can lead to differential effects on cognitive profiles (3;4;10;11;13;14). This is further complicated by the fact that there is no reliable biomarker for FASD. Consequently, the cognitive profile forms the primary focus of investigation (3;4;11;15-17). Whilst these cognitive features are characteristic for FASD, they are not specific to FASD (10;18). The use of a behavioural phenotype approach to study the effects of different aetiological disorders on clinical neurodevelopmental consequences has increased in interest and popularity recently. Several authors have highlighted the benefits of this approach to identify what is unique to a disorder but also what features overlap between different disorders (10;18).

Recognition at different ages

Whilst in utero, alcohol exposure is associated with an increased risk of developing FASD, although not every foetus that is exposed suffers damage. A complex number of factors interact to define individual risk (4;10;11). This can result in a wide individual variation in presentation. This includes the time at which the symptoms present and also when these symptoms are diagnosed.

Unfortunately, as highlighted, many of the symptoms of FASD are not specific to these disorders and many symptoms can be seen in isolation in a wide variety of other conditions. As such, recognising FASD clinically can cause difficulty for both professionals and families. This complexity led to the realisation that guidance was required at different stages to identify the disorders (19-28).

Why is there a need for a Medical & Healthcare Professional Network and consensus statement in the UK?

The extent of medical professionals' knowledge of FASD in the UK remains unclear. In view of this, and to try and improve recognition, it was decided to establish a professionals' forum of people working in different specialties. An early objective of this group was to bring together a consensus of opinion as well as to create a focus of learning and development for FASD in the UK.

Over two days, on the 12th and 13th of October 2011, the first meeting of this group took place. As part of that meeting an afternoon was spent considering the ways in which FASD presents at different stages of life, what barriers existed in NHS care and what the pathways to care should look like in the UK. This report forms the basis of the findings of that meeting.

Part 2:

Consensus Meeting Process and Outcomes

Process

Aims: What it was hoped would be gained by the meeting and what it was not meant to achieve.

The meeting was originally set up to establish the clinical processes in the UK for FASD. This included areas such as where to get a diagnosis and the barriers that existed to obtaining this. It was not intended, at this stage at least, to reconsider diagnostic guidelines or to establish management processes. These types of meetings had already been undertaken internationally with experts who had been involved in FASD work for many years (29). It was therefore considered inappropriate at this stage for a UK meeting to try to replicate this. It was considered that diagnostic guidelines and management processes may well be secondary factors that would be touched upon and discussed but would not form the main focus of the meeting.

The main aim and the main outcome of the meeting was to establish a process and comprehensive care pathway that built upon the clinical expertise of clinicians in the room who were familiar with different levels of the NHS structure and from different professional backgrounds.

Participants

The conference was advertised to medical professionals via direct and indirect advertisement. Those interested made contact with The FASD Trust on a first come basis to attend the conference. Only medical and healthcare professionals were in attendance at the conference and they are the only contributors to this statement. A wide range of professional backgrounds involved in the care of people with FASD were represented at the meeting and are listed above.

Prior to the consensus debate, a series of educational talks and workshops were held to update the participants about the current scientific knowledge about FASD. This was facilitated by UK-based and internationally-recognised experts in the FASD field, and included presentations from affected families.

Session structure

Five broad age groups were identified as common periods of presentation. These were the peri-natal period, early years, primary school, secondary school and adults. For each of these areas a professional commonly working with that age group was identified to facilitate the discussion. These professionals had shown commitment and practice in the field of FASD in the UK. These discussions took place around five semi-structured questions. Individuals self-selected into a particular group based on their areas of experience and expertise. The smallest group number was eight with the largest being twenty.

Free discussion was allowed and the discussions were recorded on a flip chart by a member of the group. These findings were then presented to the whole group where other additional comments were added. The different records were then annotated.

Semi-structured questions used in each group

- Typical symptoms and signs at that age
- Information required at that age
- Barriers to diagnosis
- When to make the diagnosis
- When not to make the diagnosis
- Limitations to diagnosis at that age
- Recommendations to overcome this
- Guidance from clinicians

Analysis of Recording

A thematic analytical approach was used to analyse the data. This was transcribed and verified and was entered into NVIVO Version 8. Initial coding was made by RM. Initial wider themes were identified before more selective coding of the data was conducted as described by Bazeley (30).

Findings

From the five different groups, thirteen broad themes were initially identified. These were subsequently condensed into these five main themes:

- The need for early diagnosis
- Challenges to diagnosis
- Lack of information
- Need for further knowledge and education
- A need to change policy and develop services

Quotes taken from Groups by Theme

Theme 1: The need for an early diagnosis

As soon as possible but need all signs to be present

Identification as early as possible

When there is enough information to be confident

As early as possible

Early enough to develop transition plan to secondary school

To support transition

Theme 2: Challenges to diagnosis

Diagnosis of exclusion, therefore need to rule out other disorders as well

Diagnostic labels such as ADHD, ASD and Attachment Disorder already ascribed so people do not look for FASD

Many similar signs to ASD and complex neurodevelopmental disorders

Not fit into a single box

Lack of or poor prenatal information or poor antenatal records

No connection between maternal and infant records

Lack of information in general

If you can only get alcohol problem as hearsay then cannot confirm diagnosis but can diagnose possibility only. Need to have the paediatric records better coded so it can be followed up more robustly.

Theme 3: Lack of information

Good information from obstetrics including information about drugs and alcohol

Robust systems for transfer of documented information from antenatal notes to baby notes.

Something needs to be done about the inability to access maternal medical notes

Identification and transfer of information from antenatal to postnatal

Referral at birth for alcohol-exposed babies

Any pre-birth case conference should always consider alcohol history

Alcohol history of the mother

Lack of information

- *Alcohol*
- *Birth circumstances*
- *Family history*

Lack of, or poor, prenatal information or poor antenatal records

No connection between maternal and infant records

Lack of information in general

Theme 4: Need for further knowledge and education

Education about the danger of alcohol on the fetus

- *School Education*
- *Sex Education*

Young people health education topics in PSE

Professionals not making the link between alcoholism and potential effects on the individual

Train midwives in history collection and working with mothers in this area

Social workers education

GP and obstetricians paying more attention to this

Inconsistent use of diagnostic tools

Lack of professional awareness and skills to diagnose/ manage the condition

Not asking about drinking in pregnancy

Increase the awareness of professionals

Theme 5: A need to change policy and develop services

Stigma prevents people making /thinking about the diagnosis.

Change in attitudes of professionals and public

Stigma of diagnosis

Oversensitivity to the information of one parent

Need to be seen in adult neurodevelopmental services as they develop.
Until then may need to be seen in adult psychiatry/ LD if commissioned.

Postcode lottery

What difference is a diagnosis if no services are available?

Lack of services for this age group

Questions about what difference a diagnosis will make

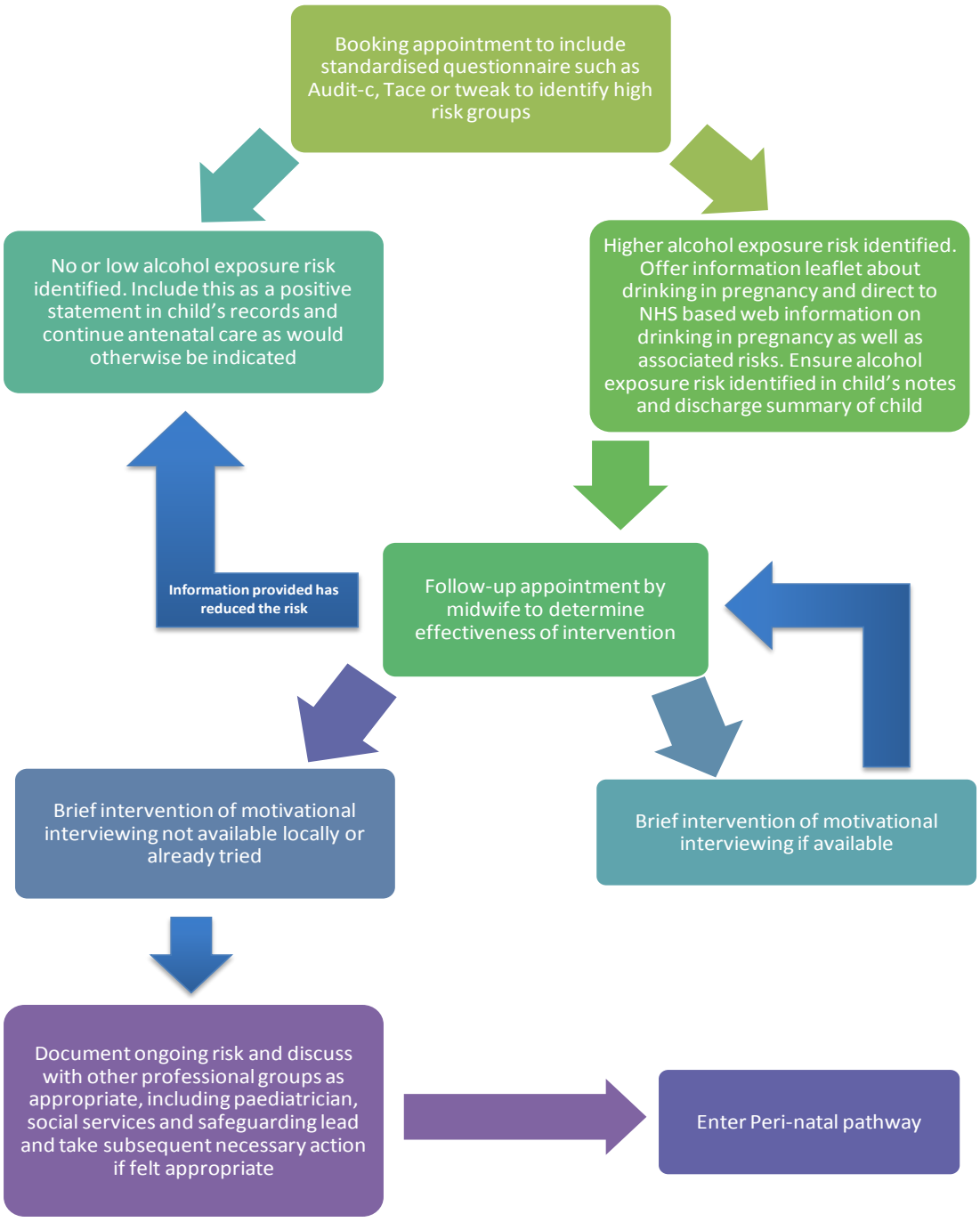
Guidance as to what to do, including National Institute for Health and Clinical Excellence (NICE) guidance

Medical school / royal college curriculums

Education of all health professionals and inclusion on curricula

Main Outcome of the Consensus Meeting: Proposed care pathways in the UK for FASD and prenatal alcohol exposure

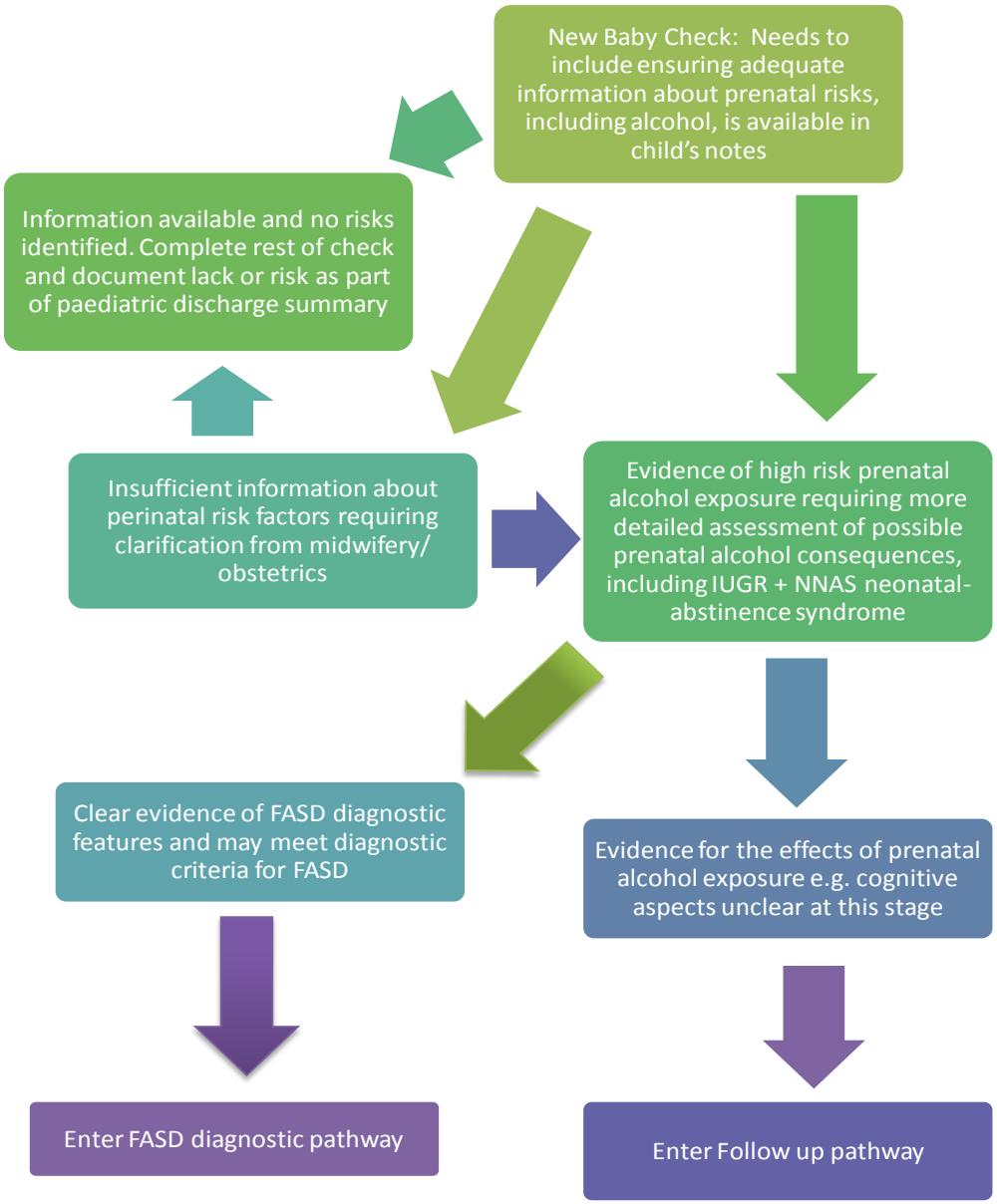
Antenatal care



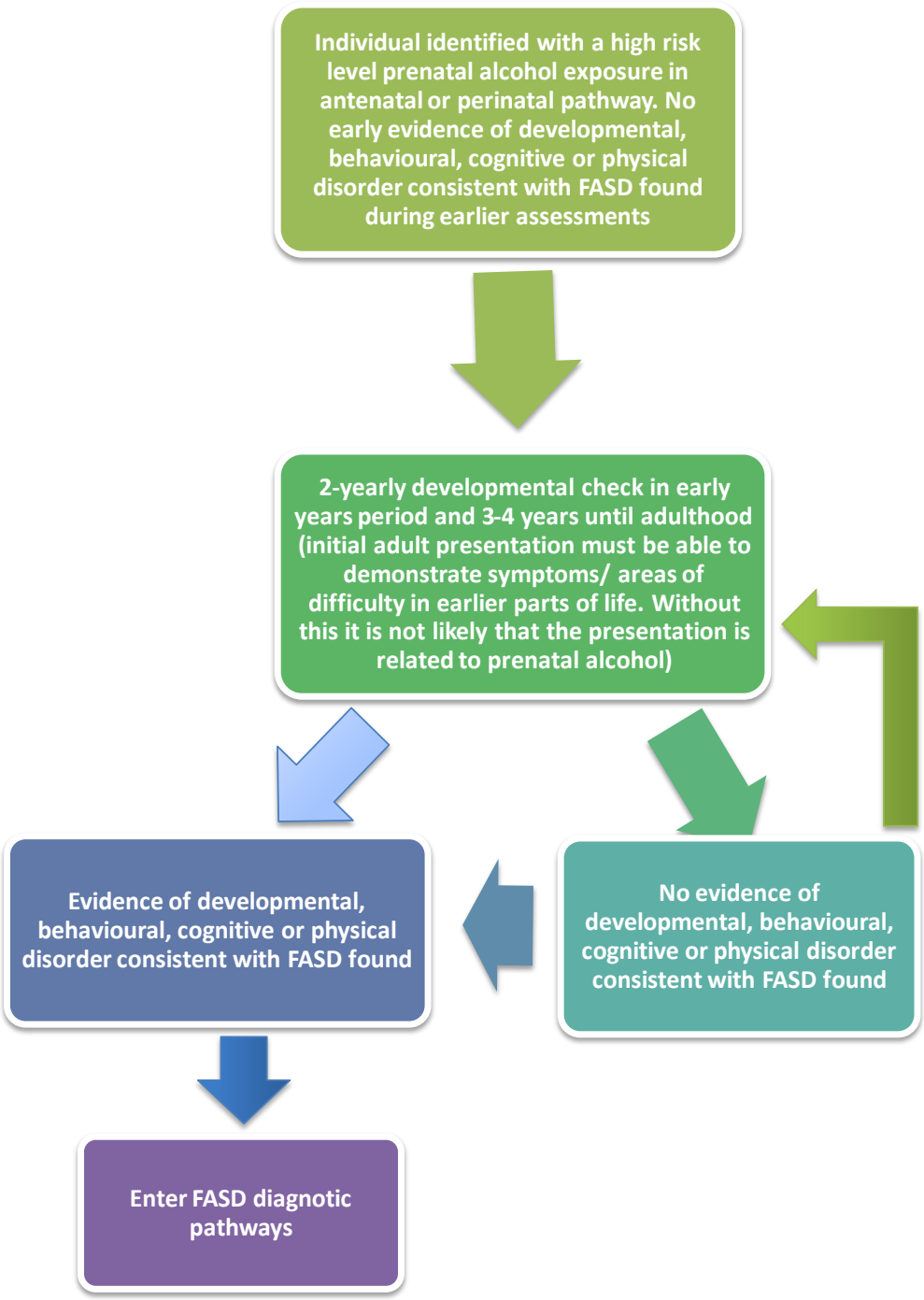
Perinatal care

It is essential the following should be documented at discharge:

1. Alcohol exposure or lack thereof
2. Growth (length, weight, head circumference)
3. Presence of any clinical features (major and minor malformations, abnormal behaviour)

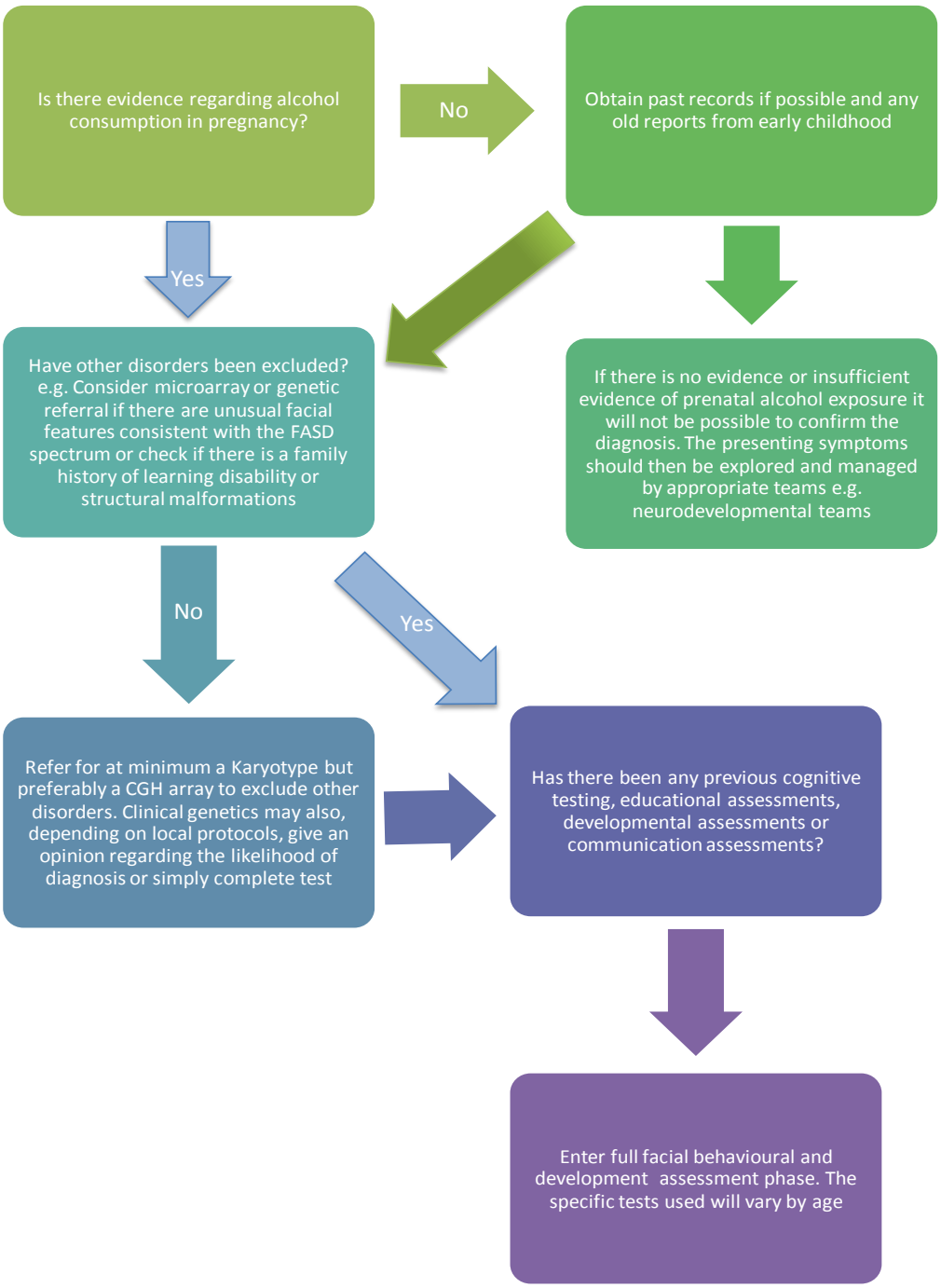


Follow-up Pathway



FASD Diagnostic Pathway

Information Gathering Stage



Facial, Behavioural and Developmental Assessment

As highlighted above, the specifics of the actual developmental assessment were considered to be part of an age-dependent developmental assessment using tools that are appropriate at specific stages. For example, some tests used on adolescents and adults such as executive function tests may not be valid in younger children and tests used in earlier years may not be as sensitive to the difficulties experienced in later years, therefore it is not possible to be too prescriptive.

The diagnostic process is also well documented. It was agreed that the process descried by Chudley et al in their 2005 guidance (6) would be adopted for use in the UK as it combined the best of the other methods. This should be supplemented by evidence to exclude other factors through genetic testing as highlighted in the pathway and consistent with recent publications (31). By ruling out other factors that present with similar behavioural phenotypes it strengthens the reliability of the diagnosis that is made.

The diagnostic process will be a tiered one with different layers of expertise. The tests, whether screening or more detailed, will depend on the setting and resources in the location in which the assessment is taking place. Appendix 4 lists the tools used by different people at the meeting and can be used by professionals to support their work.

Discussion

The findings of this process suggest that there is still a long way to go in the UK before we are at a stage where clinical services are able to effectively address the needs of individuals with FASD. The outcomes highlight the need to begin from preconception. GPs, family planning clinics and midwives need to take a lead role, alongside obstetricians, to ensure that good advice and education are provided and that those people who are drinking at a high risk level are identified.

Only by passing on information, however, can the needs of individuals be met later in life. Whilst the presentation may change, those crucial pieces of information such as risk of alcohol and drug exposure, their timing and frequency, all need to be passed on for the diagnosis and subsequent management strategies to be developed at any stage of an individual's life. Failure to do this only leads to increased difficulties, both for the individual and for the professionals involved. The barriers to accessing these records remain prominent as, for some, the information is seen as third party information. These issues will need to be worked through, with the considerations of medical ethics taken into account. Indeed, it may eventually require legislation to help this. Different healthcare groups will need to come to a consensus about what is considered confidential information to a mother and what is relevant to a child related to that mother. Clearly, not all information can be passed on without consent, however some pieces of information should be deemed crucial.

The lack of knowledge that exists within both the general public and amongst medical professionals needs to be addressed through training and support. In addition, documents such as this will need to be expanded upon to offer guidance to clinicians as to what to look for at each stage of presentation, who to refer to, what strategies help, and what strategies do not help.

Multiple changes need to be implemented. Firstly, there needs to be policy change to introduce into the educational curriculum at an early stage, for example in PHSE lessons, more reliable and up-to-date information about the effects of prenatal alcohol exposure. Secondly, information needs to be aimed at Universities and Royal Colleges so that education about the effects of prenatal alcohol is consistently taught on undergraduate and postgraduate medical and healthcare curricula.

The exclusion of other disorders, such that the diagnosis is truly one of exclusion as well as inclusion, remains a crucial part of this pathway. As recently highlighted, the use preferably of a CGH array test will increase the reliability of a FASD diagnosis if other causes of behavioural difficulty are ruled out. (31). Referral to a genetic service should be particularly considered when confronted with a family history of learning difficulty, structural malformations or unusual facial features not consistent with the diagnosis.

Not all people who have alcohol exposure will go on to have identifiable difficulties and, in extreme cases, sufficient difficulties to be labelled a disorder. Women should not be made to feel guilty. However, it should be acknowledged early if a child develops complications through potential exposure to alcohol and a process followed to provide early intervention. It is the lack of input that often leads to secondary

disabilities (32). The care pathways above highlight the proposed model of clinical practice that is considered to offer best practice in the UK.

More work will need to be completed as the evidence base improves. For example a NICE review of what is and what is not known in the wider literature. This has been completed in other countries and lessons learnt from those areas will be crucial for the development of services in the UK.

This process represents, for the medical group who helped develop it, only the beginning of a process of change. These recommendations are primarily clinical pathways to guide a process. Whilst on the whole they are evidence-based and in keeping with current best practice internationally, they may need to be evaluated to ensure that they represent both quality to the NHS and also value for money. It does form the basis, however, for better recognition and also intervention for a vulnerable group that can be a high economic burden to society and also an at-risk group of secondary harm if missed.

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Part 3:

Supplementary Appendices

Appendix 1: Verbatim notes taken from different working groups' flip chart records

Peri-natal years

Primary Prevention

Education about the danger of alcohol on the fetus
School Education
Sex Education
Family planning clinics
Fertility Clinics
Support of professionals: trusts to have lead professionals e.g. Substance abuse midwife, lead obstetrician, neonatologist or paediatrician
Needs for Royal college of Psychiatrist (poss. perinatal psychiatrist) support

Secondary Prevention

Identification as early as possible
Training issue for midwives arising about alcohol consumption of mothers and partners in pregnancy .
Treatment: Consider dietary supplements in mothers who continue to drink
Information: Robust systems for transfer of documented information from antenatal notes to baby notes.
Clarify mechanisms to pass on information about suspected risks of FASD to adoptive parents
Something needs to be done about the inability to access maternal medical notes or pregnancy notes or GP notes at the time of adoption ?? ethical issues re consent
Any pre birth case conference should always consider alcohol history

Targeted Screening

Enquire about alcohol consumption routinely in mothers of babies with IUGR
Routine discussion of risks for next pregnancy with parents of babies diagnosed with FASD

Recommend: Repeat antenatal growth scans in alcohol exposed babies: look for what?

Postnatal Firm diagnosis of FAS usually cannot be made

Essential the following should be documented

1. Alcohol exposure, with attempt to document as reliably as possible in units of alcohol
2. Growth (length, wt, head circumference)
3. Presence of any clinical features
4. Lip/philtrum score using Likert scale

Those with significant alcohol exposure to be referred to community paediatrician for follow up

Community paediatrician to consider

Chromosomal analysis/ microarray
Genetics referral if facial features unusual and not consistent with FAS, family history of learning difficulty or structural abnormality
Photographs
Growth monitoring
Recognition of these babies grow slowly
Health surveillance rather than discharge in at-risk children as symptoms and signs evolve over time
Need for a trans-generational approach to identify 'at risk' (i.e. psychiatric/ developmental/ alcohol dependence) mother who may have further children exposed to alcohol

General Principles

Identification and transfer of information from antenatal to postnatal
Referral at birth for alcohol exposed babies

Early years group (age 6months – 4 years)

Symptoms and signs

Delayed motor development
Feeding difficulties
Irritability
Sleep problems
Temperamental difficulties
Hyperactivity
Demanding; "high Maintenance"
Failure to thrive
Short attention span
Cautious
Fearful,
Aggressive behaviour

Poor coordination
Delayed speech
Disinhibition
Care provider relationship difficulties
FAS Phenotype
ARBD
Cleft Palate
Hypertonia / Hyptotonia
Delayed visio-motor coordination
Chronic Otitis Media
Seizure Disorders
Unilateral Sensory loss
Strabismus
Nystagmus due to optic nerve hypoplasia
Regulatory problems in infancy seen with sensory integration problems

Information Needed

Good information from obstetrics including information about drugs and alcohol
Neonatal history
Full developmental history and initial health assessment
Family history
Health visitor information or community nurse
Social services history (although concern about consent was raised)
Medical records of infant and mother)
Preschool nursery history and findings
Expert court reports
Issues of shared care between birth parents and foster parents , especially if ' risk' factors in birth home environment.
Birth mother history
Early photographs
Red book
Previous Growth Charts
Previous relevant medical investigations
Genetic tests

When to make Diagnosis

As soon as can but need all signs to be present

When not to make diagnosis

No information about Alcohol
Diagnosis of exclusion therefore needed to rule out other disorders as well.

Limitations

Difficulties get Alcohol Hx
Lack of documentation in hospital, GP, Red book
Adoption from other countries
Unclear clinical developmental delay
Lack of facial features
Stigma of diagnosis
Oversensitivity to the information one parent
Issue of obtaining consent from those with parental responsibility to access notes and take photograph

Recommendations

Train Midwives in History collection and working with mothers in this area
Make sure all standard ante-natal pro-formas have a space to write alcohol consumption including number of units per week. If necessary provide a key to what constitutes a unit alongside this box
Social workers education
GP and obstetricians paying more attention to this

Check list for diagnosis needs to be created
Antenatal exposure history essential to be passed on
Consistent message related to prevention
Document FAS /ARND diagnosis early

Primary School

Presentation

LD
Poor self esteem
Hyperactivity
Inattention, sleep disturbance
Social communication disorder
Oppositional behaviour
Language processing difficulties
Not fitting into any box
Bullying, being bullied
Emotional disturbance
Sensory disturbances
Planning difficulties
Short stature
Attachment poor
Facial features

Poor coordination
Other physical problems e.g. heart problems, Eye problems, cleft lip/ palate

Information needed

What do parents think?
Antenatal history and neonatal history
Red book, any hair strand/ meconium tests (is this widely done?0
- Social history
- Occupations
- Social service involvement with child including safeguarding

Alcohol history of the mother
Domestic violence
Family history
- Alcohol and drug use
- Learning difficulty
- Siblings
- Parental health
- Consanguinity

School Feedback/ therapist reports
Early developmental history and milestones
Team around the child reports
Early year's reports/ CAHMS reports
Hearing tests
Health visitor/ GP notes with child and mother

Barriers to diagnosis

Lack of information

- Alcohol
- Birth circumstances
- Family history

Worse if this is an overseas adoption or if it is greater than 5 years since the adoption

Inconsistent information

Constraints around social work chronology. Expert reports only available after medical reports are written
Different social work teams
Late bookings in pregnancy
Diagnostic labels such as ADHD, ASD, and Attachment Disorder already ascribed so people not look for FASD.

Questions about what difference a diagnosis will make
Inconsistent use of diagnostic tools
What difference a diagnosis if no services available?
Parental denial
Lack of joint working between services with split between those working for mother and those for the child
Conventional history taking inadequate
Childs perception
Impact of the diagnosis on the child in a mainstream school. Label, stigma
Privacy of social and medical information
Lack of general awareness around the diagnosis
Lack of biological markers
Different levels of acceptance and knowledge about FASD#

When to make a Diagnosis

As soon as possible especially if care proceedings
Barriers need more consideration especially in biological family
As soon as possible especially if having more children
Early enough to develop transition plan to secondary school

When not to make a diagnosis

When not enough information
When other causes are not excluded

Tests to consider
Chromosomes, CK, Uric Acid, FBC, LFT, U+E, TFT

Child with normal IQ need to consider implications and impact

Recommendations

Public education: School, Family planning, warning on bottles

Education of all health professionals and inclusion on curricula

Antenatal: ask regularly about alcohol
Leaflets/ posters

Child recording of risk e.g. in red book

Information sharing
Better information gathering
Pathway approach so more info before seen

Secondary School

Signs and symptoms

Many similar signs to ASD and complex neurodevelopmental disorders

Behaviour

Inattention and risk taking
OD
Hyperactive and impulsive
Sexual inappropriate behaviour
Conduct disorder
Criminal activity and involvement wit justice system
Self harm and suicide attempts

Learning

Poor achievement especially maths
School exclusion
Disorganised behaviour
Bullying
Mixing up of memories getting things wrong way round
Memory difficulties short term
Variable iq and mixed profile
Functional lifestyle difficulties

Communication

Social interaction: interested in but cannot make or keep friends
Better expressive than receptive language
Poor social use of language

In adolescence

Anxiety and depression
Exploitable
Vulnerable to alcohol and rug use
Outbursts and lack of empathy
Sleep problems
Self harm

Physical features change with age (midface fills out)

Short stature may remain but not as much as earlier years
Motor problems will remain but more fine motor than gross
Possible cardiac deficits ongoing

Family

Stress
Blame and shame
History of bipolar and depression

Information required to make a diagnosis

Alcohol exposure and knowledge of other teratogens
Family circumstances in care
Peri-natal/ Antenatal history
Redbook birth charts needed
Parental IQ/ functioning and family history
AS much antenatal history as possible

Sibling history
Education and social history
Previous and other diagnoses made
Previous assessments conducted
Medication used and effects
Youth justice information
Photos from earlier life

Barriers to diagnosis

Lack of or poor prenatal information or poor antenatal records
No connection between maternal and infant records
Lack of information in general
Obtaining assessments
Lack of professional awareness and skills to diagnose/ manage the condition
Not asking about drinking in pregnancy
Confirmation/ tertiary referral barriers to support secondary care
Lack of confidence
Lack of interpersonal liaison and sharing of information
Poor access to cognitive assessments and others
Transition between adult and child services
Transition between paediatric and MH services

When to make diagnosis

As early as possible
When there is enough information to be confident but also linked to awareness/ training and skills of professionals

When child and family are ready, although preferably asap to maintain contact with family not sure what this means
When something to offer
To support transition

When not to make a diagnosis

Diagnosis of exclusions
Uncertainty
Support by tertiary opinion referral colleague's genetics

Limitations

Not fit into a single box
Multiple diagnoses
Missed opportunity to intervene
Lack of engagement with young person
Challenging placements
Information is not an issue as good sources
Lack of services for this age group
Secondary disabilities already established

Recommendations

Increase the awareness of professionals
Events
Courses
Medical school / royal college curriculums

Increase awareness in public
Young people health education topics in PSE
Tertiary centres for support possibly fitting in with wider neurodevelopmental centres
Interpersonal working/ collaboration
OT services
Create pathways interdisciplinary management
Protocols
RCPCH adolescence section

Adults

What it looks like

Often present with the ARND aspect and behaviour with secondary disability
Come in because of needing benefits: (presentation)
Can present differently to other cases with diagnoses so presentation make you think other factors involved

Present with offending and recidivist behaviour.
Often suspicion, not full fact.
May well have also had numerous other problems, attachment, trauma complicates presentation
May also have been own substance abuse.
People who are addicted themselves

Information needed

Need the detail of the information
Alcohol history maternal
Previous diagnoses looked for
Educational history and progress
Reports done in past
Behaviours in pregnancy
Not always in single source
Degrees of disability known
Maternal history

Barriers

Question about if it makes a difference.
How would it be possible to get
Getting antenatal history difficult
Family may not be around any more
Time available for consultation. As a GP
Professionals not making the link between alcoholism and potential effects on the individual
How to differentiate those who are presenting with alcohol cause and other reasons
Not a phenomenological diagnosis and social management thus questions the need of what to do.
Not knowing where to get help
Who should be seeing this unclear as adults.
IQ does not relate to function
Stigma prevents people making /thinking about the diagnosis.
Knowing what process to use.

How to get over barriers

Asking and thinking standard about alcohol exposure from very early stage
Need to be become consistent in recording of information at earlier stage
Need to be seen in adult neuro-developmental services as they develop.
Until then may need to be seen in Adult psychiatry/ LD if commissioned.
Change in attitudes professionals and public
Guidance as to what to do including NICE guidance for
To make it a diagnostic label that is accepted as a way of accessing support and help
Legislation

When to make the diagnosis

AS a GP not right to make the diagnosis, but should be accepting and think about diagnosis
Refer to geneticist in the fist instance
Refer to regional neuro-developmental service if possible
Refer to adult psychiatry or LD psychiatry (currently not commissioned)
Tertiary service services should support diagnosis as needed
Good transition planning from child to adult services

Limitations to diagnosis

Limited amounts of information available.
Inconsistency in data recording and where this is recorded.
Not having good accurate alcohol history
Records not easily available and not accessible
Records in the maternal records. Confidentiality
Interventions not available
Postcode lottery

Recommendations to overcome this

Thinking more commonly in standard histories about maternal alcohol exposure to see if it is an issue. Should be part of standard family history

If can only get alcohol problem as hearsay then cannot confirm diagnosis but can diagnose possibility only Needs to have the paediatric records better coded so it can be followed up more robustly.

Paediatric discharge summary needs to have complication s and risk factors in pregnancy including alcohol with grades of risk
Standardisation to how information is recorded. (standard use of reed code)
Method of linking mother and individual for potential future prevention

Need to pick up high risk cases much earlier on as they go through to help diagnosis at different stages of transition including at transitional reviews. This will prevent new adults presenting in the future.

Ensuring that there is a consistent place of where information is recorded.

Needs to have access and understanding in the wider psychosocial community on ongoing basis

More evidence bases for interventions

Appendix 2: Methods of Diagnosis: core features and deficits

As highlighted in the table taken from Chudley 2005 (Table 2), there were initially two broad sets of diagnostic criteria in existence. These are those developed by the Institute of Medicine (IOM) and the 4 Digit Scoring created by the University of Seattle. The Centre for Disease Control then subsequently published its own guidance. The Canadian guidance outlined the overlaps between the initial two and brought together aspects of the 4 Digit and IOM codes to offer clinicians a practical guide as to how they might be used in routine practice (Table 4).

It is important to clarify for any teratogen that not every individual who is exposed will develop symptoms of the disorder associated with that exposure. The diagnostic criteria look at different aspects of the condition, for example facial features. In reality, however, the criteria are only valid if taken as a whole. There are for example people in the general population who will have been exposed to alcohol at a critical period of facial development but not have received the persistent alcohol exposure necessary to have effects on cognitive development. That group, though exposed, will not have FASD. The same is true for all alcohol levels to which a foetus is exposed. There has been no specific level of alcohol exposure in pregnancy that has been shown to be safe. The majority of people will only have significant cognitive deficits consistent with a diagnosis of FASD, however, if they have moderate to high levels of alcohol exposure during the pregnancy. It should be noted that individual risk remains unclear with mixed finding in studies, meaning that some risk will always remain following alcohol exposure levels other than abstinence.

The consensus reached at this meeting was that, whilst there remains debate around the correct guidance, a cautious approach should be taken to recommendations. Increasingly, it has been recognised that to use a consistent approach to diagnosis, using an already developed approach is preferable rather than trying to establish UK guidelines. It was considered better to adopt the approach established by the Canadian group which has already considered how to bring together the diagnostic methods that currently exist.

Appendix 3: Diagnostic Criteria

The Care Pathways in the next section describes diagnostic criteria at different ages. Taken from Chudley 2005 (6).

Table 2: 4-Digit Diagnostic Code criteria for FASD

Rank	Growth deficiency	FAS facial phenotype	CNS damage or dysfunction	Gestational exposure to alcohol
4	***Significant*** Height and weight below 3rd percentile	***Severe*** All 3 features: PFL 2 or more SDs below mean Thin lip: rank 4 or 5 Smooth philtrum: rank 4 or 5	***Definite*** Structural or neurologic evidence	***High risk*** Confirmed exposure to high levels
3	***Moderate*** Height and weight below 10th percentile	***Moderate*** Generally 2 of the 3 features	***Probable*** Significant dysfunction across 3 or more domains	***Some risk*** Confirmed exposure. Level of exposure unknown or less than rank 4
2	***Mild*** Height or weight below 10th percentile	***Mild*** Generally 1 of the 3 features	***Possible*** Evidence of dysfunction, but less than rank 3	***Unknown*** Exposure not confirmed present or absent
1	***None*** Height and weight at or above 10th percentile	***Absent*** None of the 3 features	***Unlikely*** No structural, neurologic or functional evidence of impairment	***No risk*** Confirmed absence of exposure from conception to birth

Note: PFL = palpebral fissure length; SD = standard deviation.

Table 4: Harmonization of Institute of Medicine (IOM) nomenclature and 4-digit diagnostic code ranks for growth, face, brain and alcohol history

	4-digit diagnostic code ranks			
IOM nomenclature	Growth deficiency	FAS facial phenotype	CNS damage or dysfunction	Gestational exposure to alcohol
FAS (with confirmed exposure)	2, 3 or 4	3 or 4	3 or 4	3 or 4
FAS (without confirmed exposure)	2, 3 or 4	3 or 4	3 or 4	2
Partial FAS (with confirmed exposure)*	1, 2, 3 or 4	2, 3 or 4	3 or 4	3 or 4
ARND (with confirmed exposure)	1, 2, 3 or 4	1 or 2	3 or 4 (2 for < 6 years)	3 or 4

Note: ARND = alcohol-related neurodevelopmental disorder; CNS = central nervous system; FAS = fetal alcohol syndrome.
Source: Developed by Kwadwo Asante and Julianne Conry
*Any final 4-digit code that can be made with these combinations of numbers and that is not also an FAS code signifies partial FAS. Combinations of face 2 that include two significant facial features also meet criteria for partial FAS.

Note: UK Growth charts use the 2nd and 9th percentiles and thus should use these cut-offs rather than the 3rd and 10th as stated above.

Appendix 4: Measures to use to during assessment

Below are common psychometric measures and their appropriateness for usage in order to quantify and classify deficits associated with FASD, allowing further management. Note: this not a complete list and reflects the types of tools used by people at the consensus meeting to employ as part of the care pathway above.

Further information on reliability, validity and methods of purchasing the below tests are available from:

Harcourt Assessment: http://www.harcourt-uk.com/index.aspx,
Nfer-Nelson: http://shop.nfer-nelson.co.uk/
National Autistic Society:
http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=128&a=3280&view=print

Early Developmental Tests

Developmental screening tests such as the Denver Developmental Screening,
Schedule of Growing Skills,
Bayleys Developmental Assessment Scales
Griffiths Developmental Scales

General Cognition

WAIS *(Wechsler Adult Intelligence Scale)
WISC (Wechsler Intelligence Scale for Children)
NART (National Adult Reading Test)

Executive Function

Denis Kaplan tests
Wisconsin Card Sort
Stroop test
BADS (Behavioural Assessment of Dysexecutive Syndrome)

Quantifies the deficit areas of executive function. This is one of the core areas of deficit and a good understanding of the difficulties seen here are essential to management of the condition.

Communication

British Picture Vocabulary Scale
CELF IV (Clinical Evaluation of Language Fundamentals)

The receptive language difficulties compared to expressive not only belie true ability but hide the vulnerability of the group; these tests are essential to management.

Associated Diagnoses / Functional Assessment
Social Communication Questionnaire
Strengths and Difficulties Questionnaire

Diagnostic Interview for Social Communicatory Disorders
Autism Diagnostic Interview
Autism Diagnostic Observation Schedule
ADHD Scales e.g. Conner's, Browns
Developmental Behaviour Checklist
Childhood Behaviour Cheacklist
Vineland II
Adaptive Behaviour Assessment Schedule
Connors ADHD tools
Mental Health Screening Tools.

Provides diagnoses in associated categories for which FAS is an aetiological condition. It is essential to understanding the wider phenotypic outcomes of the condition as well as the functional level of the disorder.

Appendix 5: Programme for UK FASD Professionals network residential programme

Day 1

08.30-09.30: Registration
Chair: Dr Takon
09.45-10.00: Introduction to Network: Dr Takon
10.00-10.45: Overview of FASD in the UK.
Where we have come from and where we are now: Dr Mukherjee
10.45-11.05: Coffee
11.05-11.50: Epidemiology, Diagnosis and Physical findings of FASD :
Bronwyn Kerr
11.50- 13.00: Cognitive profile and difficulties recognising phenotype of FASD :
Ed Riley
13.00-14.00: Lunch
14.00-14.10: Introduction to afternoon :Dr Mukherjee
14.20-15.20: Workshops
15.20-15.40: Coffee
15.40-17:50: Workshops Continue
Workshop 1: Practical measuring the face, rulers and cameras:
Raja Mukherjee / Daniella Mandelli
Workshop 2: Behavioural interventions for FASD: Ed Riley
Workshop 3: Practical difficulties in obtaining histories: Mary Mather
Note - delegates will be split into 3 groups to rotate around workshops

Day 2

08.00 -09.00: Breakfast networking opportunity
Chair: Moira Plant
Families: Input from affected families
09.30-10.00: A Birth Mum's Story: P Williams
10.00-10.20 Bringing up Children: Simon & Julia Brown
10.20- 10.40 Adults with FASD: P & S Jackson
10.40-10.55: Coffee
10.55- 11.45: Overview of medication usage in FASD and associated conditions:
Kieran O'Malley
11.45 -12.45: Case Studies: Small groups
12.45-13.45: Lunch
13.45-15.00: Development of Consensus Clinical guidelines - Diagnosis and Recognition of FASD: Panel

This document has been printed by The FASD Trust, a charity which exists to support those affected by FASD and to raise awareness of the condition.

To obtain additional copies of this Consensus Statement, to learn more about The FASD Trust's UK Medical & Healthcare Professionals Forum, including membership forms and to access other resources, please contact The FASD Trust at:

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